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TECHNOLOGY-DEPENDENT CHILDREN: HOSPITAL v. HOME CARE

A TECHNICAL MEMORANDUM

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Foreword

This technical memorandum is about problems arising out of success. Recent advances in medical technology have permitted sick children who once would have died to survive with the assistance of sophisticated equipment and intensive nursing care. Often, the assistance is needed for just a short time, but sometimes the dependence on life-sustaining technology is permanent. As technology for helping keep children alive has improved, a new population of technology-dependent children has emerged.

This small but growing population of children raises new problems for the health care system. Because the care is expensive—often more expensive than most American families can afford—children and their families depend on third-party payers—insurance companies, Medicaid, or philanthropists—to finance the needed care. But the structure of the health insurance system has not kept pace with the needs of these children. Most technology-dependent children are eligible for Medicaid coverage in the hospital, but coverage of home care is more limited. Consequently, some children have remained hospitalized even when their families are able to provide good, lower cost care in the home.

OTA was requested by the House Energy and Commerce Committee and the Senate Labor and Human Resources Committee to examine the problems of health care financing encountered by technology-dependent children as part of a larger assessment, *Technology and Children's Health.* The committees wanted to know how many children are technology dependent, how home care and hospital care compare in cost, and how well private and public third-party payers cover the services needed by these children.

This technical memorandum provides a working definition of technology dependence and estimates the prevalence of technology dependence among American children. A principal finding is that the size of the population varies dramatically with the clinical criteria used in the definition. OTA has also found that the cost-saving potential of home care depends to a great extent on attributes of the family and the home environment. The ability and willingness of family members to provide ongoing nursing care for a substantial part of the day are central to lowering costs to third-party payers, although they may require great sacrifice on the part of the family.

The conduct of this study was guided by the advisory panel for the OTA assessment, *Technology and Children's Health,* chaired by Harvey Fineberg. In addition, many government officials and health care professionals were consulted. Information and insights provided by parents of technology-dependent children were also very helpful. Key OTA staff involved in the analysis and writing of the technical memorandum were Elaine J. Power and Judith L. Wagner.

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NOTE: OTA appreciates and is grateful for the valuable assistance and thoughtful critiques provided by the advisory panel members. The panel does not, however, necessarily approve, disapprove, or endorse this technical memorandum. OTA assumes full responsibility for the technical report and the accuracy of its contents.

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Contents

Page
Chapter 1: Summary 3
Introduction 3
Summary of Findings 3
  The Population 3
  Relative Effectiveness and Costs of Home v. Hospital Care 5
  Sources of Financing for Home Medical Care 7
Implications 9

Chapter 2: The Size of the Technology-Dependent Child Population 13
Introduction 13
Problems in Defining the Population 14
Estimating the Prevalence of Technology Dependence 16
  OTA's Working Definition 16
  Data Sources and Sampling Problems 17
  Estimating Prevalence 19
  Estimates 20
Trends in the Population 26
  General Trends in Chronic Illness and Disability 26
  Future Changes Due to New Maintenance and Treatment Technologies 28
  Changes in Medical Practice 28
Conclusions 31

Chapter 3: Comparing Effectiveness and Costs of Home v. Hospital Care 35
Introduction 35
Effectiveness 35
  Evidence of the Effectiveness of Home Care 35
  Factors Influencing the Quality and Effectiveness of Home Care 36
Cost 37
  Components of Home Care Costs 38
  Issues in Comparing the Costs of Hospital and Home Care 42
  Evidence 43
Conclusions 46

Chapter 4: Sources of Financing 51
Introduction 51
Private Health Insurance Coverage for Technology-Dependent Children 51
  Extent of Coverage 51
  Adequacy of Coverage 52
Medicaid 55
  Background Issues 55
  Special Options for Financing the Home Care of Technology-Dependent Children Under Medicaid 59
  State Use of Medicaid Options to Serve Technology-Dependent Children 64
  Practices Limiting Use of the Medicaid Options 66
State-Provided Services for Children With Special Health Care Needs 67
A Comparison of Home Care Benefits in Five States: Three Hypothetical Cases 71
  Case 1: "K" 72
  Case 2: "M" 73
  Case 3: "T" 73
Department of Defense 75
Other Public Programs and Services 76
Charitable Organizations 77
Conclusions 77

Appendix A. Acknowledgments 81
Appendix B. Workshop Participants and Agenda 83
Appendix C. Implications of the Population Definition 85
Appendix D. Alternative Settings of Care 88
Appendix E. The Educational System as a Source of Health Care Services and Funding 92
Appendix F. Glossary and Acronyms 94
References 99

Boxes

Box *Page*
A. Profile of a Ventilator-Dependent Child 15
B. Bronchopulmonary Dysplasia 29
C. Changing Technology in the Neonatal Intensive Care Unit 30
D. Individual Benefits Management Among Private Insurers 56
E. Reimbursement for Subacute Care in California 91

Tables

Table No. *Page*
1. Summary of OTA Estimates of the Size of the Technology-Dependent Child Population, 1987 4

Contents—continued

Table No. *Page*
2. The Population of Children Currently Served in Programs Emphasizing Alternatives to Hospital Care . . . 16
3. Major National Health Surveys and Data Systems . . . 18
4. Data Sources Used as Bases for OTA Estimates . . . 19
5. Estimates of the Number of Ventilator-Dependent Children . . . 20
6. Estimates of the Number of Children Requiring Parenteral Nutrition . . . 21
7. Basis for Estimate of the Population of Children Requiring Extended Intravenous Drug Therapy . . . 23
8. Basis for Estimate of the Number of Children Requiring Other Nutritional and Respiratory Support . . . 24
9. Estimated Prevalence of Selected Chronic Conditions in Children, Ages 0 to 20, 1983 . . . 25
10. Estimated Incidence of Bronchopulmonary Dysplasia, 1984 . . . 29
11. Checklist of Respiratory and Infusion Skills for Home Care Patients and Families . . . 39
12. Supplies Needed for Four Home Infusion Therapies . . . 39
13. Sample Home Respiratory Care Costs That Were Reimbursed by a Third-Party Payer, 1985 . . . 40
14. Summary of Comparative Average Monthly Charges Presented in the Literature of Ventilator-Dependent Individuals in Hospital and Home Settings . . . 45
15. Comparative Charges for Home v. Hospital Administration of Intravenous Antibiotics as Reported in the Literature . . . 46

Table No. *Page*
16. Number and Percent of Children Aged 0 to 12 Years Covered Only by Private Health Insurance, by Income Status, United States, 1986 . . . 52
17. Surveys of Employer-Sponsored Group Health Insurance Plans . . . 54
18. Medicaid Hospital Inpatient Stay Maximums and Units of Payment in the 50 States and District of Columbia, 1985 . . . 58
19. Summary of Medicaid Home Health Services Provided in 50 States and the District of Columbia, 1984 . . . 60
20. Comparison of State Medicaid Options for Expanded Home- and Community-Based Care . . . 61
21. State Activity in Medicaid Home- and Community-Based Service Options as of Apr. 15, 1986 . . . 65
22. State Policies and Practices That Limit Participation Under the Regular Waiver Programs That Theoretically Could Serve Physically Disabled Children, April 1986 . . . 68
23. State Policies and Practices That Limit Participation Under the Model Waiver Programs, April 1986 . . . 69
24. State Policies and Practices That Limit Participation Under the State Plan Amendment, April 1986 . . . 70
25. Total Amount of Expenses Allocated for Programs of Selected Foundations, 1979 and 1980 . . . 77
26. Some Conditions That May Lead to Dependence on Respiratory or Nutritional Support . . . 86

Chapter 1

Summary

Chapter 1
Summary

INTRODUCTION

Long-term dependence on expensive and sophisticated health technology, and its use in settings other than the acute-care hospital, is not new. The polio epidemics of the first half of this century led to the use of respiratory rehabilitation centers (131), and by the end of the 1950s there were over a thousand polio survivors requiring respiratory support living at home (102). Since then, sophisticated technologies such as hemodialysis, intravenous feeding, and now intensive ventilatory care have been moved home. With each have come newly recognized needs for patient and family training and, increasingly, full-time complex nursing care.

Unlike the children who were part of the earlier polio population, the present population of technology-dependent children is a diverse group of individuals with a great range of medical diagnoses, many of them very rare. These children require a broad array of technologies and have similarly diverse care and nursing needs. Without recent advances in medical technology,[1] many of these children would not be alive. Positive-pressure ventilation, using machines that force air into the lungs through a face mask or through a surgical opening directly into the trachea (windpipe), began to be used regularly on hospital patients outside the operating room in the 1950s (31). The sophistication of these devices and their management to make them suitable for long-term use on infants fueled the subspecialties of neonatology and critical care pediatrics in the 1960s (69). New intravenous feeding technologies were added to the neonatologists' repertoire over the next decade; the first person in the United States to respond to long-term total intravenous feeding was an infant born without a functional intestine in 1968 (46). But it is only since the beginning of the 1980s that more than a handful of hospitals and physicians have begun to consider the home environment appropriate for high-risk, technology-dependent children.

When these sophisticated medical technologies should be used, how and where they should be provided, and who should pay for them are currently subjects of public debate. To provide some of the foundation for this debate, this technical memorandum addresses four specific questions. They are:

1. Who are the technology-dependent children?
2. How many technology-dependent children are there in the United States?
3. What services do these children require, and what are the costs and effects of receiving those services at home rather than in institutional settings of care?
4. To what extent does private and public insurance cover the services needed by technology-dependent children?

---

[1] Medical technology is defined as the drugs, devices, and medical and surgical procedures used in medical care, and the organizational and support systems within which such care is provided.

SUMMARY OF FINDINGS

The Population

"Technology-dependent" is a term used to describe a small subset of the disabled child population who rely on life-sustaining medical technology and typically require complex, hospital-level nursing care. In this technical memorandum, **the technology-dependent child is defined as one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability.** This definition is independent of the setting of care or the particular credentials of the caregiver. The ongoing nursing care, usually required for substantial parts of each day, may be provided by a professional nurse or by a trained and skilled parent or other lay caretaker.

This definition can apply to a wide variety of cases, ranging from children requiring the continuous assistance of a device and highly trained caretaker to those requiring less frequent treatment and intermittent nursing care. Where one draws the line on this continuum largely determines the size of the population categorized as technology dependent. OTA identified four separate populations, distinguished from one another by their clinical characteristics, that might reasonably be considered technology dependent:

- Group I: Children dependent at least part of each day on mechanical ventilators.[2]
- Group II: Children requiring prolonged intravenous administration of nutritional substances or drugs.
- Group III: Children with daily dependence on other device-based respiratory or nutritional support, including tracheostomy tube care, suctioning, oxygen support, or tube feeding.
- Group IV: Children with prolonged dependence on other medical devices that compensate for vital body functions who require daily or near-daily nursing care. This group includes:
  - —infants requiring apnea (cardiorespiratory) monitors,
  - —children requiring renal dialysis as a consequence of chronic kidney failure, and
  - —children requiring other medical devices such as urinary catheters or colostomy bags as well as substantial nursing care in connection with their disabilities.

The first three groups are narrowly defined and limited to children whose technology dependence is both life-threatening and requires frequent and complex nursing tasks. The fourth group of children is less susceptible than the others to long-term hospitalization, largely because the frequency or complexity of required nursing care is substantially lower than for the first three groups. Under a very strict definition of technology dependence, this fourth group might not be included. OTA has included it to demonstrate how rapidly the technology-dependent population grows as additional groups are included in the definition.

Table 1 presents OTA's estimates of the prevalence of technology-dependent children in each of the four groups. Precise estimation of prevalence is impossible because of data limitations, so a range of estimates is provided for each group. **Table 1 makes it clear that the number of technology-dependent children is quite small (less than 17,000 children) when the definition is limited to Groups I-III but increases dramatically when Group IV is included.** Furthermore, a large number of additional children not captured by this device-based definition of technology dependence require at least as great a level of care as the children in Group IV. These children include the proportion of children with chronic diseases such as diabetes, hemophilia, and epilepsy who require constant or very frequent nursing care as a consequence of the complexity and quantity of drugs and therapy they receive. If the definition of tech-

Table 1.—Summary of OTA Estimates of the Size of the Technology-Dependent Child Population, 1987

Defined population	Estimated number of children
Group I:	
Requiring ventilator assistance	680 to 2,000
Group II:	
Requiring parenteral nutrition	350 to 700
Requiring prolonged intravenous drugs	270 to 8,275
Group III:	
Requiring other device-based respiratory or nutritional support	1,000 to 6,000
Rounded subtotal (I+II+III)	**2,300 to 17,000**
Group IV:	
Requiring apnea monitoring	6,800 to 45,000
Requiring renal dialysis	1,000 to 6,000
Requiring other device-associated nursing	Unknown, perhaps 30,000 or more

SOURCE: Office of Technology Assessment, 1987.

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[2] In this technical memorandum, ventilators refer both to devices that apply negative pressure, such as the "iron lungs" that were used to treat polio patients, and to devices that use positive pressure to force air into the lungs.

nology dependence were broadened to include these chronically ill children, the population of technology-dependent children might be several times again as large.

In large measure, medical practice and parental attitudes determine how many technology-dependent children exist. In an area where parents and physicians are aggressive in managing high-risk infants, terminally ill children, and severe trauma victims, many children may survive with long-term technology dependence. In contrast, such children may die or may subsist with less intensive long-term support in areas where treatment is less aggressive due to social preference, customary practice patterns, a lack of facilities, or low payment. The physician's decision regarding when to wean a child from a life-sustaining device such as a mechanical ventilator also affects the number of technology-dependent children, and there are large variations in weaning practices among different physicians and different hospitals.

There is little evidence regarding the proportion of technology-dependent children who are hospitalized, except that it seems to vary widely among States. Children currently cared for at home generally meet discharge criteria such as a capacity for self- or family care; supportive, stable home environments; and funding for necessary equipment, supplies, and professional nursing services. Those who remain hospitalized are less likely to meet these criteria.

The population of technology-dependent children has increased in both size and visibility over the past 25 years, and it will probably continue to increase for several more. In 1960, only 3 out of every 10 very-low-birthweight (under 1,500 g) newborns survived for at least a month; by 1980, nearly twice as many were surviving (170,171). Most newborn infants in this weight group require at least temporary respiratory assistance, and the increased survival rate has certainly increased the rate of technology dependence. In fact, much of the survival is a result of that technology. Twenty-five years ago, the technology for long-term intravenous nutrition did not exist; now, children who have never been able to digest food are surviving to adulthood.

New technologies, such as improvements in the ability to prevent chronic lung disease in newborns, could reduce the size of the population, but they will not have substantial effects on the incidence of respiratory dependence for at least 2 to 5 years. Meanwhile, the number of very-low-birthweight infants surviving will probably continue to rise, increasing the total number of children with respiratory dependence. The spread of acquired immunodeficiency syndrome (AIDS) in the U.S. population will increase the number of children with dependence on intravenous nutrition and medication. Aggressive treatment of patients with ultimately fatal diseases such as cystic fibrosis and muscular dystrophy, and of infants with intestinal tract disorders that would otherwise be fatal within days, also is becoming more widespread. These developments will expand the population of children who are dependent on respiratory and nutritional technologies well into adulthood. Payment policies that adequately cover long-term care for these children will strengthen this trend. Thus, it is likely that the incidence[3] of dependence on the technologies used by children in Groups I, II, and III may as much as double in the next few years, stabilizing or even declining somewhat in later years. Long survival of those who are dependent, however, means that the total number of technology-dependent children will probably not decline.

Relative Effectiveness and Costs of Home v. Hospital Care

Little objective evidence exists on the relative effectiveness of home v. institutional care on the medical status and development of technology-dependent children. Hospitals have generally been considered the most appropriate and effective setting for complex medical care, while the family home has been considered the most appropriate and effective setting for child growth and development. Considerable experience has been gained in moving complex medical care into the home in recent years, with much success. Many parents and health care professionals now consider the home preferable to an institution as a setting of care for even the most technology-dependent child whenever home care is possible.

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[3] Incidence is the number of new cases during a specified period of time. Prevalence, by comparison, is the total number of cases during a period of time.

Effective home care is not an unqualified achievement, however. First, and most importantly, effective home care requires that parents want their child home. Second, families must be able to cope with living with the child and the intrusions on their own private lives as a consequence of the many other people also involved in the child's care. Third, the effectiveness of home care depends on the quality of services that are provided to the family. These include:

- adequate family training and preparation,
- professional caregivers trained in the relevant nursing skills,
- appropriately designed and well-maintained equipment,
- adequate social and psychological support services,
- high-quality respite care,[4]
- appropriate home renovation,
- appropriate transportation,
- locally available emergency facilities, and
- competent case management services.[5]

Thus, while most family homes can be expected to be appropriate and effective settings of care for technology-dependent children, a few will not be effective for reasons inherent in the family situation. Some others can be effective only if especially strong social support and nursing services are provided. Reducing the level or quality of these services decreases the cost of home care to third-party payers (at least in the short term), but it also decreases home care effectiveness. Inadequately prepared families and home environments (as might sometimes occur in very aggressive early discharge programs) are likewise a threat to high-quality, effective home care.

The costs of caring for technology-dependent children are both high and highly variable. In the hospital, these costs depend largely on the duration of dependence and the intensity of need for medical care. The care of ventilator-dependent children tends to be most costly in acute-care hospitals because these children typically require the very intense level of nursing found in intensive care units; less expensive institutional care can usually be found only in special respiratory units of rehabilitation or long-term care facilities. Other technology-dependent children can be cared for in a variety of hospital settings, and some require a level of care that can be provided by a skilled nursing facility. However, nursing homes and other nonhospital facilities that accept young children and are equipped to serve their needs are rare.

The costs of home care depend less on the child's clinical condition and more on the attributes of the family and home environment. In the home, families have tended to bear a relatively high proportion, and third-party payers a relatively low proportion, of the total costs to society. This situation has occurred because the families of these children have provided most of the highest cost services—nursing and housing—themselves.

The care of many technology-dependent children is likely to be least costly both to society and to public or private insurers when it is provided at home. **Because the cost of home care depends so heavily on social and environmental, rather than medical, factors, it is not possible to identify a specific group of technology-dependent children based on clinical criteria alone for whom home care will be cost saving to third-party payers. However, if a child is medically stable, the home has a good potential for being a less expensive setting of care than an inpatient facility.** If family members are willing and able to provide some or most of the required nursing care, and if the child will be home long enough to offset the one-time startup costs such as training and renovation, the home is very likely to be the least expensive setting of care for insurers. However, the use of family members to care for these children can involve very high costs to the family in terms of lost income, career opportunities, leisure time, or time for routine household tasks. Reducing these costs to the family—e.g., by paying for a nurse when parents work outside the home—raises home care costs to the payer.

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[4] Respite care is any care designed to give the family some relief from constant caregiving.

[5] Case management is the coordination and oversight of the package of health care and related services provided to an individual.

A few technology-dependent children cannot or should not live at home. For these children, foster care, hospital care, or other institutional care must be sought, and the relative costs and quality of care in these settings must be evaluated. Foster home care is often sought for children whose natural parents cannot provide their care, although this setting raises costs to the government over care in an appropriate natural home. It may be preferred over institutional care, but it is likely to be difficult to find foster placement for all technology-dependent children who need it. Other potential settings of care are:

- transitional or subacute wards of acute-care hospitals,
- rehabilitation or chronic care hospitals (particularly specialty wards of these hospitals),
- subacute care facilities,
- pediatric skilled nursing facilities, and
- specialized community group homes (which may sometimes be considered "group" foster homes).

In many areas, few or none of these alternatives may be available. Yet they are important alternative sources not only of long-term care, but of transitional and respite care.

Sources of Financing for Home Medical Care

Both public and private payers have expanded the coverage of alternative care options for technology-dependent children in the past 5 years. However, payment for nonhospital care is still hindered by lack of coverage and poor coordination between private and public payers.

Technology-dependent children are more likely than other children to lack adequate private insurance. When they are insured, their benefits often do not cover their extraordinary expenses, particularly in the home, and they are likely to use up their families' insurance benefits rapidly. High lifetime maximum benefits (e.g., $1 million rather than the still common $250,000) and case management while under private insurance can extend private coverage, so long as the parent does not lose employment. Ultimately, however, virtually all very-long-term technology-dependent children requiring a high level of nursing assistance will exceed the limits of their families' private insurance policies, will be uninsurable in the self-purchase insurance market because they are poor risks, and will end up on Medicaid. Poor technology-dependent children, or those whose families are uninsured, must turn to Medicaid from the start.

In most States, Medicaid does not routinely pay for full-time home nursing and other complex home medical services. Nor are many technology-dependent children normally eligible for Medicaid until their families have become impoverished. Since 1981, however, the Federal Government has permitted States to waive certain Federal rules regarding eligibility and services, allowing States to provide alternative mechanisms (separate from States' regular Medicaid programs) to pay for intensive home care for technology-dependent children. Three alternative options[6] are currently available to States:

1. regular 2176 "home- and community-based services" waivers, under which States can provide augmented Medicaid services to specified populations;
2. model 2176 waivers, a subset of the above waivers that can be targeted to very small and specific populations; and
3. amendments to State Medicaid plans to waive certain restrictive eligibility income requirements for individuals who meet specified criteria.

As of April 1986, 14 States had model 2176 waivers directed specifically at technology-dependent or other severely physically disabled children.[7] Ten States have now amended their State plans to extend Medicaid eligibility to more children in this population (59).

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[6] Between 1981 and 1984, individual waivers of Medicaid eligibility restrictions were also awarded to a few technology-dependent children across the country. These waivers are no longer awarded, although a number are still in effect for the children who received them. Approximately 14 States still have children served under individual waivers (59).

[7] The exact number of States serving technology-dependent children under these waivers is unknown. States may cover such children under their 2176 waivers but not actually serve any; and many States were renewing their 2176 waivers in 1986, with some new provisions.

Although these options have enhanced the availability of Medicaid services to technology-dependent children, Medicaid still suffers from two general problems regarding home care coverage for this population. First, the Federal Government prohibits States from providing waivers of the usual Medicaid rules if program costs would increase by doing so. If Medicaid hospital payments in a State are routinely restricted (as, for example, when Medicaid limits the number of covered hospital days), it can be very difficult to show reductions in Medicaid costs when extensive home services are necessary. This restriction prevents many technology-dependent children from receiving home services. Second, apart from the waivers, States cannot offer expanded benefits to a small, defined population; once covered, a service must be made available to any Medicaid beneficiary who needs it. Both Federal and State governments have feared that expanding services to technology-dependent children would mean greatly increased expenditures as other beneficiaries also use these services. Medicaid's experience with expanded home benefits for the elderly has been that these benefits tended to increase, rather than decrease, program costs.

Where States have used available options to cover home care for technology-dependent children on a case-by-case basis, they have had some success in both increasing effective services and decreasing costs. However, neither States nor the Federal Government are too willing to put in place more general programs where costs will not be so tightly controlled. For the same reason, States have even been cautious in applying the waiver and State plan amendment options.

On the other hand, States are sometimes using Medicaid funds in ways that may not be strictly in line with Federal regulations in order to serve technology-dependent children more effectively. Many States find the Federal Medicaid rules increasingly complex and difficult to understand and implement.

Because the federally supported State Services to Children with Special Health Care Needs (CSHCN) programs[8] offer more flexibility in implementation, a number of States have chosen them as the primary vehicle to provide and coordinate home services to technology-dependent children. The role of CSHCN as the source of case management and coordination for children served under Medicaid waivers has been particularly strong in some States (47). The CSHCN programs are more commonly perceived as active supporters of care for the disabled than is Medicaid. However, the freedom that allows State CSHCN programs to choose which groups of children they will support (e.g., ventilator-dependent children) also allows for extreme variation among States in available services, and variation within States regarding which disabled children receive extensive assistance. Other public programs (such as home-based social services) and services provided by charitable organizations supplement existing payment for home-based medical care to varying degress across States and localities. **Thus, the availability of home medical care and related services depends on the State in which the child lives and his or her particular medical condition. A technology-dependent child may receive adequate services in one State through Medicaid, in another through the CSHCN program, in another through a combination of diverse sources, and in a fourth not at all.** A child requiring intravenous nutrition may have access to adequate home services in one State, while one who needs mechanical ventilation in that same State may receive no home services at all. And even if the child lives in a State where home benefits to serve his or her medical condition are theoretically adequate, the child's family may be given insufficient or conflicting information regarding the availability of those services.

Where adequate coverage of home medical services is available, other problems have begun to arise. As well-compensated alternatives to hospital care become more widely available, payers have incentives to limit the availability of hospital care for technology-dependent children, and hospitals have increasing incentives to discharge them, *even if the family is not adequately prepared to take the child and no other options have been developed*. This danger is both very real and very great.

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[8] Until recently, these programs were referred to as Crippled Children's Services (CCS).

IMPLICATIONS

Home care is not only feasible and desirable for many technology-dependent children but in many cases can also reduce costs incurred by insurers. Consequently, interest in extending home care benefits to technology-dependent children is likely to increase. A difficult question for third-party payers is how to offer such benefits. Enhanced home care benefits could be offered to all beneficiaries, but this strategy would substantially increase insurance costs and might discourage efficient use of such services. If insurers choose to offer enhanced benefits to a narrowly defined set of beneficiaries, issues of fairness arise. There are no clinical criteria that can neatly separate children who deserve such benefits from those who do not. **The definition used in this technical memorandum which is based on the use of a medical device, does not capture all children who need substantial nursing care in the home.** It is not necessarily directly applicable in an insurance context.

Any expansion of home care benefits is likely to increase the number of technology-dependent children at home and will have important secondary effects. These will include:

- *Increased early discharge from neonatal intensive care units*. Some hospitals are beginning to encourage earlier discharge of premature newborns (24). Increased payment for home nursing, home phototherapy, apnea monitoring, and other services are likely to strengthen the trend.
- *Increased numbers of technology-dependent children discharged to homes before families feel prepared to accept them*. Overenthusiasm in discharging children to the home could have very serious consequences for the health of these children. Quality of care could be seriously impaired if children were discharged home without adequate long-term nursing support, equipment maintenance, and backup plans if home care becomes infeasible.
- *Problems in the quality of nursing care and equipment support in the home*. A shortage of trained professional nurses and inadequate equipment-related support is already reported in some places. The shortage could get much worse if financing availability outstrips service availability. The lack of uniform guidelines and technology-related skill certification among home care nurses will exacerbate the difficulty in obtaining skilled, high-quality nursing.
- *Increased charges for home services*. Greater demand for high-technology home care services offers opportunities for home health agencies to enter this field with high prices, particularly in geographic areas where there is little competition or in areas where professional nurses trained in these techniques are in great demand.
- *Greater-than-anticipated costs to payers due to the "woodwork effect."* To at least some extent, enhanced home care benefits will replace family care rather than hospital or other institutional care. This is certainly desirable to most of the families involved and may prevent later institutionalization of many children. Nonetheless, this factor will tend to increase program costs above what was originally anticipated.
- *Increased demand for appropriate foster care or institutional care*. Few options exist outside of the acute-care hospital for children who cannot return to a family home. Availability and payment for care in small group homes, pediatric nursing facilities, and other facilities is likely to become a significant issue. The need for a source of respite care outside of the home will add to the demand for appropriate facilities.
- *Increasing numbers of technology-dependent children attending public schools*. More children living outside of institutions will lead to more children in the schools. However, there are no Federal or State guidelines regarding who pays for the health care needed by these children while attending school, or who bears liability for any adverse effects they suffer in this setting. A lack of resolution of these issues could needlessly prevent many technology-dependent children from attending school.
- *Need to better define the role of case man-*

ager and to ensure that the manager is in a position to balance the interests of the family, the third-party payer, and other involved parties.

The population of technology-dependent children is one with a constant undercurrent of change. Although "technology-dependent" has often been used as a euphemistic label for children whose home care was expected to be less expensive than institutional care, changes in technology and underlying diseases continually alter its character. Children needing dialysis for kidney failure do not raise the same concerns as children needing ventilation, for the most part because payment for dialysis services is largely assured and outpatient or home care has become routine in most cases. New approaches to medical practice and health care financing may yet accommodate the most complex of today's and tomorrow's technology-dependent children as well.

Chapter 2

The Size of the Technology-Dependent Child Population

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The Size of the Technology-Dependent Child Population

INTRODUCTION

Although the technology-dependent population is frequently discussed, it has never been defined. Simply put, technology-dependent[1] children are a vaguely defined subset of the much larger disabled child population. **In this technical memorandum, the term "technology-dependent" refers to those children who use a medical technology (embodied in a medical device[2]) that compensates for the loss of normal use of a vital body function, and who require substantial daily skilled nursing care to avert death or further disability.**

This definition has four important characteristics. First, medical devices are used as a basis for defining the population, because device use is observable. Second, OTA is including only life-sustaining technologies in the definition. A great many other children exist with extensive health care needs, but they are not included here. Third, the dependence is assumed to be prolonged. "Prolonged" is not defined directly, and its meaning varies somewhat with the type of technology, but it is assumed not to include situations such as a premature newborn who outgrows the need for ventilation after only a few weeks. Finally, "skilled nursing care," as used in this technical memorandum, means any care that requires highly technical nursing skills, including care provided by nonprofessionals such as parents trained in these skills.[3] Technology-dependent children often have mental, behavioral, or emotional disabilities in addition to the above characteristics, but they are set apart by the level and nature of care—both in terms of medical device support and skilled nursing care—required by their chronic physical disabilities.

This chapter begins with a description of some of the problems encountered in defining technology dependence and the use of this term by others.[4] The chapter then translates the general definition into a working definition for the purpose of estimating the number of technology-dependent children. Four clinically distinct groups of children are identified. Three are unquestionably technology dependent under the general definition; the fourth group meets the technical definition of technology dependence but has nursing needs that are substantially lower than those of the first three groups. (App. C presents some potential implications of this working definition. Those implications are not discussed directly in this chapter.)

The central part of this chapter presents the existing evidence on how many children are in each group. Finally, the chapter describes trends in the population at risk of technology dependence, particularly evidence on changes in the number and survival of children with chronic diseases, high-risk infants, and children with progressive, terminal illnesses.

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[1] Some people prefer the term "technology-assisted" to the term "technology-dependent," but the latter term has been more common in recent legislation and is used in this technical memorandum.

[2] A medical device is any instrument, apparatus, or similar or related article that is intended to prevent, diagnose, mitigate, or treat disease or to affect the structure or function of the body (161).

[3] Nursing services are generally recognized as a group of medical services that cannot be performed by the average person without considerable training. They differ from custodial and personal care services (e.g., dressing, bathing, or feeding a patient) which less trained people can perform safely.

[4] The development of this chapter was greatly aided by the discussion at a workshop conducted by OTA on the subject. The workshop agenda and a list of participants are included in app. B.

PROBLEMS IN DEFINING THE POPULATION

The need to define the technology-dependent child population arises not from any inherent attribute of this group but from the organization and priorities of the health care payment system in the United States. The home health care benefits of most third-party payers—private insurers, State governments, and Federal health programs—have been limited both in scope and in amount. The adaptation of sophisticated medical devices and services to the home setting were likewise limited. Over the past decade, however, the adaptation of these technologies to the home has greatly expanded. Today, there are children with very high long-term hospital costs who could be cared for at home with such technology if payment for that intense level of home care were available. Many third-party payers have come to pragmatically define technology-dependent children as those children whose care is likely to be very expensive, who could safely be cared for at home given sufficient services, *and who are likely to cost less to the payer* if cared for in this environment. But such a definition does not provide clinical or functional criteria for identifying technology-dependent children. Rather, it is a criterion for case-by-case waivers of a payer's usual limits to home health benefits and services.

This pragmatic, payment-based definition presents a serious problem because it excludes seemingly similar technology-dependent children who might benefit greatly from nonhospital care, but who may cost more in the home due to their particular family or home characteristics. Moreover, this pragmatic definition provides no basis for estimating the number of technology-dependent children, even the number who would fit the definition as stated, because there exists no systematic way to count such children.

Legislation introduced in 1985 attempted to provide more specific definitions of "technology dependent." S. 1793 defined a "medical technology dependent child" as "an individual under the age of 21 *who has a medical condition (specified by the Secretary in regulations)* which would require inpatient hospital services in the absence of home or community-based care, and who is dependent upon medical technology in order to avoid death or serious injury" (emphasis added). In contrast, H.R. 2703 would have provided home care benefits only to ventilator-dependent people, irrespective of age. These persons would be eligible for benefits if they required a ventilator at least 6 hours per day; had required this technology for a month while in a hospital or skilled nursing facility; and would require institutionalization if the necessary respiratory services were unavailable at home.

These definitions illustrate two congressional concerns regarding a definition of the technology-dependent child population. First, the population of greatest concern is those children who, but for the availability of special services and financing, could not be cared for at home. Second, "technology" has been used to mean medical devices, rather than only skilled medical services. Both of these criteria reflect a desire to accommodate the needs of technology-dependent children while maintaining control over Medicaid costs.

The prototype of the technology-dependent child is one who cannot breathe without a mechanical ventilator (see box A). The life of such a child depends on an expensive and sophisticated piece of equipment, trained personnel to perform the necessary procedures that accompany its use, and a multiplicity of other devices, drugs, and therapies. Until very recently, such a child was nearly always cared for in an acute-care hospital until the child died or could be weaned from the ventilator, a process that could take months or years.

While all agree that the child on a ventilator is technology dependent, there is still a great deal of confusion over what other groups of children meet this description. The population of children who might be considered technology dependent is enormously diverse. Variations occur in the length of dependence; a child may be ventilator-dependent for 10 years, or 2 years, or 2 months. Care needs vary in frequency and intensity across children as well. While one child may need skilled nursing care 24 hours a day, another might need such care only 8 hours a day, or 2 times a day for 2 hours each. Some children require minimal medical equipment but a great deal of skilled nurs-

Box A.—Profile of a Ventilator-Dependent Child

Conditions leading to ventilator dependence may develop anytime in childhood or adolescence. A teenager, for example, may suffer permanent breathing impairment due to chronic illnesses such as cystic fibrosis or muscular dystrophy. Spinal cord trauma, which can damage the nerves that enable breathing, is also a fairly common cause of ventilator dependence in children and adolescents. Or, ventilator dependence may be due to breathing difficulties present at birth.

A ventilator-dependent child sometimes begins life as a premature baby, initially given oxygen and 24-hour ventilator support because he (or she) is unable to breathe adequately on his own. Since the baby is also unable to suck adequately, he must be tube fed as well. A physician may create a gastrostomy (a surgical opening into the stomach) to make feeding easier.

When attempts are made to reduce mechanical ventilation, it becomes clear that the infant cannot breathe on his own even for a few minutes. The infant's windpipe becomes irritated from having the nasal tube changed. The physician creates a tracheostomy (a surgical opening in the throat) so ventilation can be administered more directly to the lungs. A tube, which can be connected directly with the ventilator, is inserted into the windpipe; this tube must be suctioned frequently, so it does not become clogged with secretions, and changed regularly with great care to prevent infection at the tracheostomy site. Since a clogged tracheostomy tube would cut off all air, the infant must be watched constantly. The nurse must perform these duties as well as administer nutrients several times a day through the gastrostomy tube, take frequent blood samples to check the level of oxygen and other gases, administer aerosols and antibiotics to moisten the airway and prevent infection, and still offer all the normal comfort and care a newborn infant must receive. A physical therapist may begin exercises to help the infant maintain physical development; a respiratory therapist may perform procedures to help his breathing. The infant's parents may spend a great deal of time with him to hold him and learn to care for him. If circumstances permit, they may take him home.

As the infant matures, he may gradually be able to sustain breathing for longer and longer periods of time on his own and may begin to learn to eat normally. Finally, if he becomes able to both eat and breathe satisfactorily on his own, the tracheostomy and gastrostomy openings are surgically closed. No longer so dependent on equipment, he may still receive frequent treatments for respiratory infections and asthma-like attacks. He continues to receive physical and speech therapy to bring him up to the level of other children his age.

ing (e.g., a child with both uncontrolled diabetes and severe epilepsy), while others may need sophisticated medical equipment but only periodic supervision (e.g., a capable older child receiving overnight intravenous nutrients).

Because of the lack of existing criteria and the diversity of the population that might be considered technology dependent, it is difficult to distinguish technology-dependent children from the larger population of disabled children of which they are a part. As a child's disability becomes gradually more (or less) immediately life-threatening, and the frequency and level of skilled medical intervention increases (or lessens), the boundaries between technology dependence and less life-threatening disabilities blur. A child with muscular dystrophy, for instance, loses muscle strength gradually, first requiring braces, then a wheelchair, then occasional supplemental oxygen or ventilation, and perhaps finally a full-time ventilator. The process may be reversed for an infant on a ventilator whose breathing problems resolve over time.

Table 2 describes children who are presently served by several programs that offer alternatives to hospital care for severely physically impaired children. These children display a wide range of medical problems. While many are obviously technology dependent, requiring both highly sophisticated medical equipment and highly skilled and intensive nursing care, others require constant caretaking and monitoring that depends neither on expensive equipment nor on intensive medical training.

Table 2.—The Population of Children Currently Served in Programs Emphasizing Alternatives to Hospital Care

Categories	Description	Services	Sample diagnoses
Children who have *acute medical/surgical problems*	Children with acute medical/ surgical problems who are discharged early from the hospital but who continue to need individualized technical care for limited periods of time	These children may require medications, unusual feedings, monitoring of vital signs, certain forms of technical treatment, etc.	Severe infectious disease Postoperative conditions Low-birthweight infants
Children who have a *terminal illness*	Children requiring technical care for a terminal illness that is expected to result in death within 6 months.	These children may for a period of time require oxygen, assistance in feeding, and/or medication for comfort.	Terminal cancer Renal failure
Children who are *severely intellectually disabled*	Children who as the result of an illness, trauma, congenital anomaly, or hereditary disease are severely intellectually disabled so that they cannot and will not in the future be able to care for themselves.	These children require varying degrees of assistance in feeding, defecation, urination, positioning, and other personal care.	Severe microcephaly Severe post meningitis Severe hydrocephalus
Children who have *chronic medical problems*	Children who will have chronic medical problems for long periods of time and are dependent on technical care.	These children may require complex alimentation, certain medications, suctioning, catheterization, intravenous therapy, tracheostomies, equipment monitoring, prescribed therapy regimens, and/or colostomies/ ileostomies.	Chronic malabsorption syndrome Severe cystic fibrosis Multiple congenital anomalies Severe seizure disorder Dystrophies Atrophies Myasthenia Chronic aspiration syndrome Short gut syndrome
Children who have *chronic respiratory problems*	Children who will be oxygen dependent for relatively long periods of time.	These children will require oxygen and may require suctioning or cardiopulmonary monitoring	Chronic bronchopulmonary dysplasia (BPD)
	Children who need ventilation assistance for periods of time	These children will require ventilator care and bronchial suctioning. They may require cardiopulmonary monitoring and gastrostomy feeding.	Chronic BPD Post encephalitis Progressive CNS disease Tracheo-bronchial malacia Ondine's curse
	Children who are completely ventilator dependent	These children require constant ventilator care, bronchial suctioning, and cardiopulmonary monitoring and may require gastrostomy feeding.	Chronic BPD Post encephalitis Progressive CNS disease
Children who have *Central Nervous System (CNS) dysfunction*	Children who have CNS problem, either the result of trauma or CNS disease so that they cannot and will not be able to care for themselves.	These children may require assistance in physical positioning, feeding, defecation, and/or urination. (Some may also be ventilator dependent.)	Progressive CNS disease Spinal cord trauma

SOURCE: J. MacQueen, "Alternatives to Hospital Care," unpublished, Aug. 5, 1986.

ESTIMATING THE PREVALENCE OF TECHNOLOGY DEPENDENCE

OTA's Working Definition

To estimate the size of a population quickly and with reasonable accuracy, criteria are needed that can easily distinguish this population from others. Therefore, concrete characteristics (e.g., a particular diagnosis or the use of a very visible technology) should be the basis of the definition, and data sources must be available whose categories are consistent with the definition. The most easily identifiable aspect of technology-dependent children is their continual dependence on a medical device to replace or compensate for a vital body function or avert immediate threat to life. Thus, in this study, four groups of children are identified whose reliance on medical devices and nursing care for maintenance of life make them candidates for classification as technology dependent:

- Group I: Children dependent at least part of each day on mechanical ventilators.[5]
- Group II: Children requiring prolonged intravenous administration of nutritional substances or drugs.
- Group III: Children with daily dependence on other device-based respiratory or nutritional support, including tracheostomy tube care, suctioning, oxygen support, or tube feeding.
- Group IV: Children with prolonged dependence on other medical devices that compensate for vital body functions who require daily or near-daily nursing care. This group includes:
  - —infants requiring apnea (cardiorespiratory) monitors,
  - —children requiring renal dialysis as a consequence of chronic kidney failure, and
  - —children requiring other medical devices such as urinary catheters or colostomy bags as well as substantial nursing care in connection with their disabilities.

The groups are designed to be mutually exclusive. If a child requires technologies from more than one group, he or she is considered only as part of the applicable group with the lowest number. For example, a child requiring both ventilation and parenteral nutrition would be placed in Group I.

Groups I, II, and III comprise children whose characterization as technology dependent is generally accepted in discussion among parents, providers, payers, and policymakers (although the range of service needs of such children varies widely). In contrast, Group IV encompasses a broad range of children whose technology dependence is less life-threatening and requires less frequent or less complex nursing tasks. The children in this group are less susceptible than children in the first three groups to long-term institutionalization as a consequence of their disabilities, and they are not universally recognized as technology dependent. They are included here because they demonstrate how the numbers of technology-dependent children change as additional groups are included in the definition.

Data Sources and Sampling Problems

The lack of a formal definition of technology dependence, its rarity, and the difficulty in detecting it have thus far prevented any reasonable estimation of the size of the population from existing common health surveys. Table 3 summarizes a number of these surveys and the populations they describe. They are generally of two types: institution-based surveys, such as surveys of hospital discharge records (which list items such as age, diagnosis, and surgical procedures for a large sample of hospital patients); and household interview surveys, in which family members are asked about various aspects of their health. None of the information from these surveys is directly correlated with technology dependence as defined in this technical memorandum.

Approximately 2 percent of noninstitutionalized children (over 1 million children) are limited in their major daily activity (e.g., attending school) (123,124). An additional group of mentally and physically handicapped children reside in institutions. Whatever the exact size of the technology-dependent child population, it must be considerably less than this total disabled population. There are two basic approaches to estimating the size of such a small population: counting it directly, and statistical estimation based on a sample of children. Because technology dependence is rare, a sound statistical estimate would require a very large sample. As table 3 shows, there are no major national health surveys that are comprehensive enough or detailed enough to support a prevalence estimate for this population.

The primary sources of data used as the bases for the OTA estimate of the number of technology-dependent children are State-based programs (in most cases relating to home care provided under public medical aid programs) and national home nutrition program registries. Table 4 sum-

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[5] In this technical memorandum, ventilators refer both to devices that apply negative pressure, such as the "iron lungs" that were used to treat polio patients, and to devices that use positive pressure to force air into the lungs.

Table 3.—Major National Health Surveys and Data Systems

Survey or data system	Population surveyed	Periodicity	Relevant data elements	Selected limitations
National Health Interview Survey (NHIS)	Approximately 40,000 households (about 30,000 children).	Annually	Activity limitations, certain chronic conditions, hospital and physician use	Institutional population excluded, sample too small to detect very rare conditions, functional limitation measures very general
NHIS Child Health Supplement	1 child per above household (about 15,000 children)	1981; may be done in future again	Detailed perinatal and child care, child development, child health problems	Same as NHIS
National Medical Care Utilization and Expenditures Survey	Approximately 6,600 households (about 4,500 children)	1977, 1980, planned 1987	Same as NHIS plus additional data on income, insurance, medical expenditures	Same as NHIS
National Hospital Discharge Survey	Discharges from approximately 420 short-stay hospitals	Annually	Age, race, sex, medical diagnoses, procedures done in the hospital	Sample too small to detect very rare conditions, not an unduplicated count of persons, no data on outpatients, nonhospitalized children
National Ambulatory Medical Care Survey	Office visits to approximately 3,000 physicians	Annually from 1983-1981; 1985	Age, race, sex, reason for visit, diagnoses, procedures performed	Sample too small to detect very rare conditions, excludes clinic and institutional visits, not an unduplicated count of persons
National Health and Nutrition Examination Survey	Households, including about 6,000 to 7,000 children	1971-1975; 1976-1980; planned 1988	Data from physical exam and laboratory tests	Small sample, institutionalized population excluded
Birth Defects Monitoring Program	Discharges from 928 hospitals, about 22% of U.S. births	Annually	Discharge abstract data for 161 birth defect categories	May not be representative sample of births, newborn data only, cannot directly detect technology dependence
Office of Special Education	State-reported data on children served in special education programs	Annually	Number of children served by handicapping condition category	Handicapped categories very broad, categories not consistently defined among States, do not include children not served by programs
Survey of Institutionalized Persons	Persons living in facilities with average stays over 30 days	1976 only	Age, race, sex, cost of care, condition treated, physical limitations	Limitation categories very broad, noninstitutionalized population excluded, data old, analysis excluded some institutions
Census of the Population	All households; sample of institutionalized persons	Every 10 years	Age, race, sex, education, region, type of institution	No health-related functional data included, institutional categories very broad

SOURCES: F.M. Ellman, National Association of State Directors of Special Education, Inc., Washington, DC, personal communication, January 1976; M.A. McManus, S.E. Malus, C.H. Norton, et al., *Guide to National Data on Maternal and Child Health* (Washington, DC: McManus Health Policy Inc., 1986); U.S. Department of Commerce, Bureau of the Census, *1976 Survey of Institutionalized Persons: A Study of Persons Receiving Long-Term Care*, Current Population Reports Special Studies, series P-23, no. 69, June 1978; U.S. Department of Education, Office of Special Education, 9th Annual Report to Congress on the Implementation of the Education of the Handicapped Act, 1987.

Table 4.—Data Sources Used as Bases for OTA Estimates

Source	Population included	Original purpose of information collection
State data:		
Illinois	All ventilator-dependent children in State; all other children served in State program for handicapped children	State information; evaluation program for similar State programs
Louisiana	Ventilator-dependent children served in special State home care program	State information; evaluation program for similar State programs
Maryland	Children dependent on respiratory support devices who are served in special State home care program	State information; evaluation program for similar State programs
Massachusetts	People dependent on ventilators for longer than 3 weeks	Survey to determine the numer of ventilator-dependent individuals
New Mexico	All children served by State Medicaid waiver for technology-dependent children; other similar children identified in State but not eligible for the program	State information, Medicaid requirements
North Carolina	All children in State who are ventilator dependent and have been medically stable for at least 2 months	Demonstrate potential need for pediatric respiratory unit
Wisconsin	Children eligible for Medicaid home services on the basis of being disabled and at a level that would otherwise require institutionalization	State information, Medicaid requirements
American Association for Respiratory Care	Respiratory therapists nationwide via their State representatives (37 States responded); asked to provide information on all ventilator-dependent patients they were serving	Document the number of ventilator-dependent persons and the degree of institutionalization
Commercial nutrition registries	Individuals served by companies or organizations maintaining the registries between October 1984 and April 1985	Develop a database of persons on home nutritional support technologies
OAISIS registry, Oley Foundation	Patients served by hospital and community-based programs responding to a 1985 survey of such programs	Develop ongoing database of characteristics of persons using home nutritional support
Hambrecht & Quist home infusion market analysis	National hospital discharge data and detailed information from a nonrandom sample of hospitals	Provide estimates of the current and future market for home infusion technologies
Abbott Laboratories home infusion market analysis	Not specified	Provide estimates of the current and future market for home infusion technologies

SOURCES: M.J. Aitken and L.A. Aday, *Home Care for the Chronically Ill and/or Disabled Technology Assisted Child: An Evaluation Model*, unpublished, November 1985; E. Lis, Crippled Children's Services, Chicago, IL, personal communication, April 1986; K. Valdez, Human Services Department, Santa Fe, NM, personal communication, July 22, 1986; P. Tschumper, Department of Health and Social Services, Madison, WI, personal communication, July 22, 1986; G. Worley, Duke University Medical Center, Durham, NC, personal communication, July 1986; Care for Life, paper prepared for U.S. Congress, Office of Technology Assessment, 1985; Oley Foundation, paper prepared for U.S. Congress, Office of Technology Assessment, 1985; B.B. Rucker and K.A. Holmstedt, *Home Industry Therapy Industry* (San Francisco, CA: Hambrecht & Quist, April 1984); Blue Cross and Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicaco, IL: BC/BSA, January 1986).

marizes these data sources and some of their characteristics. The OTA estimates are not derived from large random samples; their validity rests on the fact that very different and independent sources of information yield estimates that are within an order of magnitude of each other.

Estimating Prevalence

The number of cases of a disease in the population can be described in three ways:

- the number of new cases during a period of time (incidence),
- the total number of cases during a given period of time (period prevalence), and
- the total number of cases at a single point in time (point prevalence).

The size of the technology-dependent population depends on which of these measures are used and, for incidence or period prevalence, the length of the period. Point prevalence is analogous to an instantaneous total count of the population. Period prevalence is more relevant to surveys, which often take several months to conduct, and to programs, which usually estimate budgets for serving a population over a period of a year. Thus, period prevalence—specifically, the estimated total number of technology-dependent children during 1987—is used in this technical memorandum.

A major problem with the data sources used in this chapter to estimate the prevalence of technology dependence is that they enumerate cases during different time periods. Some of the surveys present the prevalence of a condition (e.g., ventilator dependency) over one or more months, rather than over a year. To obtain the total prevalence in a year, one should add to this monthly total the number of new cases that arose during the succeeding months in that year. However, there is no basis for estimating how many of those new cases would arise. In such cases OTA assumes an incidence and duration of technology dependence consistent with what few data are available. That assumption is stated in the discussion of the estimate.

In deriving consistent prevalence figures from the data, OTA also uses the implicit assumption that the incidence and duration of technology dependence are stable. However, there are indications that duration of technology dependence may be increasing as children on these technologies survive longer. Incidence may also be rising with increased survival of extremely premature babies and the advent of acquired immunodeficiency syndrome (AIDS), two conditions that can lead to technology dependence. An increase in either incidence or duration of technology dependence would increase the prevalence of the population. These and related issues are discussed further in the second half of this chapter.

Estimates

Group I: The Ventilator-Dependent Population

The most soundly-based estimates are those for ventilator-dependent children. To estimate the size of this population, OTA used the numbers obtained from each of the States and organizations that have attempted to identify such children. From these numbers, OTA obtained a rate per child under the appropriate age group (e.g., under age 18) in the State. That rate was then applied to the entire U.S. child population to obtain an estimate of the number of ventilator-dependent children that would exist if every State's medical practice patterns and other relevant characteristics were similar to the reference State. To accommodate differing age boundaries, OTA provides estimates both for children under age 18 and children under age 22.[6]

Table 5 presents the estimated number of ventilator-dependent children in six States and one multi-State survey documented during the past 3 years. The populations varied considerably among the States; different States identified or reported children in different age groups, ranging from children under age 16 (Massachusetts) to

Table 5.—Estimates of the Number of Ventilator-Dependent Children

State	Survey year	Survey period	Age group	Number ventilator dependent	Rate per million children	Extrapolation to U.S. per survey period		Extrapolation to U.S. per year[a]		Percent in institutions
						Under 18	Under 22	Under 18	Under 22	
Illinois	1985	1 year	0-21	74	19.0	1,191	1,500	1,191	1,500	36%[b]
Louisiana	1986	1 year	0-21	35	23.8	1,305	1,643	1,305	1,643	13%[b]
Maryland	1985	1 year[c]	0-17	26	23.9	1,498	1,886	1,498	1,886	23%[b]
Massachusetts ..	1983	1 month	0-15	14	13.5[d]	843	1,062	1,096	1,381	86%[e]
New Mexico	1986	<1 month	0-21	4	7.4	577	726	753	948	75%
North Carolina ..	1986	1 month	0-17	7[f]	4.3	268	337	421	530	43%
AARC survey (37 States)....	1985	1 month	0-17	445	8.3	520	655	679	845	55%[d]

[a] See footnote 7 in text for explanation of conversion from monthly to annual prevalence.

[b] Illinois, Louisiana, and Maryland have active programs to place ventilator-dependent children at home.

[c] Not reported, apparently at least a year.

[d] Adjusted for 82 percent response rate. Remaining institutions were assumed similar to responding ones.

[e] Figure applies to all patients in the survey, including adults.

[f] Four of the seven children had been discharged home on ventilators during the past 3 years. It is unknown whether all four children cared for at home are still alive and ventilator-dependent, but they were assumed to be so for the purposes of this table. Thus, in converting from monthly to annual prevalence, 4/7 of the U.S. extrapolation was not converted up, since this part of the number represents a 3-year prevalence rather than a 1-month one.

SOURCES: Office of Technology Assessment, 1987. Data from K. Kirkhart, Children's Hospital, New Orleans, LA, personal communication, January 1987; M.J. Aitken and L.A. Aday, *Home Care for the Chronically Ill and/or Disabled Technology Assisted Child: An Evaluation Model*, unpublished, November 1985; K. Valdez, Human Services Department, Santa Fe, NM, personal communication, July 1986; G. Worley, Duke University Medical Center, Durham, NC, personal communication, July 1986; Care for Life, "Life Sustaining Technologies and the Elderly: Prolonged Mechanical Ventilation," paper prepared for U.S. Congress, Office of Technology Assessment, 1985.

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[6] In extrapolating estimates to the different age groups, the lower bound of an estimate assumes that no individuals between the ages of 18 and 22 require the technology, while the upper bound assumes that these individuals have this attribute at the same rate as those under age 18.

children under age 22 (Maryland and New Mexico). The operational definition of individuals on "prolonged" ventilation also varied.

The lower bound of the ventilator-dependent estimate is based on a survey conducted during one month in 1985 by the American Association for Respiratory Care. This survey yielded data from 37 States, which when extrapolated to the U.S. population as a whole yielded an estimated 520 ventilator-dependent children under age 18 that month, or roughly 680 children per year.[7] This estimate is slightly higher than the lowest State-based estimate. It is used instead of that number because of the evidence that at least a few States have much higher prevalences. The highest estimate is based on data from Maryland which imply a nationwide population of 1,886 ventilator-dependent children per year under age 22. OTA has arbitrarily increased this number by 10 percent, to 2,000, to obtain an upper estimate. This upper bound accounts for both a possible undercount of the universe of ventilator-dependent children in Maryland and for any increases in the population between 1985 and 1987.

Group II: The Intravenous Therapy Population

Parenteral (Intravenous) Nutrition.—To estimate the number of children requiring parenteral nutrition, OTA extrapolated from the available State data to the United States as a whole and compared those numbers with nutritional registry data. Extrapolations and registry figures are summarized in table 6.

The State data from Illinois, New Mexico, and Wisconsin are underestimates of the children on parenteral nutrition in these States, because they include only home patients who are monitored by these programs. However, since the universe of ventilator-dependent children is known in Illinois, and the proportion of those children served by the Services to Children with Special Health Care Needs program is also known, an estimate

Table 6.—Estimates of the Number of Children Requiring Parenteral Nutrition

Source	Basis for estimate	Comments on manipulation	Extrapolated U.S. estimate
Commercial registries, 1984-85	373 children under age 18 on home parenteral nutrition documented on one of two registries supported by home nutrition companies.	Assumed to be a national minimum estimate.	373 children on parenteral nutrition under age 18 (per 7-month period).
Illinois, 1985	5 children requiring parenteral nutrition served by State program (compared to 22 children in program on ventilators).	Total of 74 ventilator-dependent children known in entire State. Assumed children on parenteral nutrition are represented in proportion.	341 children on parenteral nutrition under age 22 (at time of program documentation).
New Mexico, 1986	2 children on parenteral nutrition served by State program (compared to 5 children in program on ventilators).	Probably not total State population of children on parenteral nutrition. Used simple extrapolation.	232 children on parenteral nutrition under age 18; 292 under age 22 (at time of survey).
Wisconsin, 1986	4 children on parenteral nutrition served by State program (compared to 5 children in program on ventilators).	Probably not total State population of children on parenteral nutrition. Used simple extrapolation.	At least 192 children on parenteral nutrition under age 18 (at time of documentation). Fewer children on parenteral nutrition than on ventilators.
Hambrecht & Quist market estimate, 1983	Estimated U.S. home care market of 2,700 patients per year requiring parenteral nutrition.	About 13% of patients in commercial registries under age 18; apply to this figure.	351 children on parenteral nutrition under age 18 in 1983 (for 12-month period); market assumed growing.

SOURCES: Oley Foundation, "Nutritional Support and Hydration for Critically and Terminally Ill Elderly," paper prepared for Office of Technology Assessment, September 1985; E. Lis, Crippled Children's Services, Chicago, IL, personal communication, April 1986; G. Cleverly, Human Services Department, Santa Fe, NM, personal communication, 1986; P. Tschumper, Department of Health and Social Services, Madison, WI, personal communication, April 1986; B.B. Rucker and K.A. Holmstedt, *Home Infusion Therapy Industry* (San Francisco, CA: Hambrecht & Quist, Inc., April 1984).

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[7] To derive an annual prevalence from a monthly one, OTA assumes an average duration of 3 years for ventilator dependence (probably low but consistent with pre-1984 data from Louisiana). The monthly incidence is then multiplied by 11 and added to the monthly prevalence to yield annual prevalence.

of the universe of children on intravenous nutrition in Illinois can be derived by assuming that the latter children are represented in the program at the same rate as the former. If children on parenteral nutrition are less likely than ventilator-dependent children to be served by this program (e.g., if Medicaid or private insurers cover home parenteral nutrition costs more comprehensively than ventilation costs), this method will underestimate the nutrition population.[8]

Equivalent calculations cannot be performed with the Wisconsin or New Mexico estimates. Nonetheless, these data provide additional evidence that there are somewhat fewer children on prolonged parenteral nutrition than on prolonged ventilation.

The commercial registries provide the most comprehensive data on children who received home parenteral nutrition. The registry data available cover only 7 months, however, and not all patients served are represented by these data. The cumulative total from this source roughly agrees with the estimate from the market analysis report. Both sources are underestimates of the prolonged parenteral nutrition population, because they assume that no such children reside in institutions. Based on these figures and the State extrapolations, OTA's estimated lower bound for the number of U.S. children receiving prolonged parenteral nutrition is 350 children per year.

An upper bound for this population would accommodate several assumptions: 1) that the population documented in the registry would have been higher had the registry covered a full year, 2) that all children served at home even during that 7 months were not documented on the registry, 3) that some additional children on parenteral nutrition reside in institutions, and 4) that the population has increased somewhat since 1985. An upper bound of 700 (double the minimum estimate) accommodates these hypotheses to a reasonable degree. However, even this upper bound may soon be an underestimate given current trends in diseases and therapy (discussed later in this chapter).

Intravenous Antibiotic Therapy and Chemotherapy.—Intravenous drug therapies are generally administered for weeks or months, rather than months or years as is the case for other technologies. They are included here because they are technologies that require substantial skilled nursing and involve issues in nonhospital care that are very similar to the issues surrounding parenteral nutrition.

Market analyses and literature reports on the number of individuals served in various home intravenous drug programs are used as the basis of estimates of the size of this portion of the Group II population, because they are the only sources available. Table 7 summarizes these sources and the estimate derived from them. The foundation of the estimate is a market analysis figure. The primary data sources and reliability of the market analyses are unreported in detail. Data from specific programs are used to estimate the proportion of the relevant population that is children. To the extent that these programs are geared towards adults rather than children, they underestimate the population. Home program numbers were adjusted by OTA to account for equivalent children not served at home.

An estimate of the number of children who receive intravenous drugs and chemotherapy is particularly sensitive to whether one is considering patients per year or patients actually receiving intravenous therapy at a single point in time. The number of cases per year is estimated here. Based on the information presented in the table, between 268 and 8,275 children receive prolonged intravenous drug therapy per year.

Group III: Children Dependent on Other Nutritional or Respiratory Support

Group III children are similar in many ways to Group I and II children. Their nursing needs are often less intensive and complex than those of children in the first two groups, however, and these children may be more likely to be served at home or in other nonhospital settings, particularly children with very-long-term dependence.

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[8] Children requiring parenteral nutrition would be more likely to have adequate home care insurance coverage than ventilator-dependent children, for example, if shift (e.g., 8-hour) nursing were an uncommon benefit. Lack of nursing is more likely to absolutely prohibit a ventilator-dependent child from going home than a nutritional-dependent child.

Table 7.—Basis for Estimate of the Population of Children Requiring Extended Intravenous Drug Therapy

Intravenous antibiotic therapy:	
Total home intravenous antibiotic therapy market, 1984 (patients/year)[a]	2,000 to 5,000
Proportion children (range given in literature reports of individual programs)[b]	4.3% to 46.6%
Implied total number of children per year on home therapy	86 to 2,330
Inflation for past exclusion of patients for home care due to financial, medical, or psychosocial reasons[c]	166%
Total number of children per year receiving prolonged antibiotic therapy	143 to 3,868
Intravenous chemotherapy:	
Total home intravenous chemotherapy market, 1984 (patients/year)[a]	2,500
Approximate proportion children[d]	5%
Total number of children per year, minimum estimate	125
California hospital discharges of children with leukemia undergoing venous catheterization (discharges/year)[e]	160
Extrapolation to U.S. (discharges/year)	1,469
Leukemia as proportion of all childhood cancers[f]	33%
Extrapolated U.S. number, all childhood cancers	4,407
Total number of children per year undergoing chemotherapy	125 to 4,407
Total intravenous drug therapy population, children per year	**268 to 8,275**

[a] See reference 137.

[b] See references 50,78,96,130,151.

[c] Up to 40 percent of all patients in the studies cited here were rejected for home therapy for these reasons. Since 4 of every 10 original patients were excluded and 6 of every 10 were included, the figure for potential home antibiotic therapy must be re-inflated by 166% to estimate the total maximum number of children that would be eligible if these barriers did not exist.

[d] A Pennsylvania report on 139 patients receiving outpatient (not home) chemotherapy gives the range of ages of these patients as 16 to 86, with a mean age of 57 (86). It is unlikely that more than 5 percent of these patients were under age 21.

[e] See reference 15.

[f] See reference 98.

SOURCE: Office of Technology Assessment, 1987.

Estimates of the number of children in Group III are derived primarily from two sources. First, the size of this population is estimated based on the prevalence of these children relative to ventilator dependence and other categories of disability in the various States. Second, registries of individuals on home enteral and parenteral nutrition programs are used as baselines to compare extrapolated estimates for tube feeding. In this case, however, comparisons are somewhat uncertain because many tube-fed patients may also be dependent on respiratory support.

From the data presented in table 8, the minimum number of medically stable children requiring Group III respiratory and nutritional support in the United States could be as low as 1,000. This would be the case if one assumed that most of the children on enteral nutritional support also require respiratory support. The upper bound, however, is much higher. Maryland data suggest that there are over 3,500 children on respiratory support (other than mechanical ventilation) alone; the high relative prevalence of Group III children in North Carolina, Wisconsin, and New Mexico indicates that these children may be more than 10 times as prevalent as ventilator-dependent children in some States. The Illinois-based extrapolation of about 2,500 Group III children is a more moderate middle estimate. Based on these numbers, a range of 1,000 to 6,000 Group III children seems reasonable. The actual number could easily reach the higher estimate if early hospital discharge of premature infants becomes more common.

Group IV: Children Requiring Other Life-Sustaining Medical Devices and Associated Skilled Care

Group IV comprises children who require life-sustaining medical devices but whose nursing care needs are generally less complex, less prolonged, or less frequent than the needs of children in Groups I through III. It includes three subgroups: 1) infants requiring apnea monitors, 2) children requiring renal dialysis, and 3) children requiring other life-sustaining medical devices in conjunction with substantial nursing care.

The Food and Drug Administration has estimated that approximately 40,000 to 45,000 home apnea monitors for infants are currently in use (173). There is considerable controversy regarding the appropriate indications for monitoring, and many of these children may be monitored for reasons not considered by all physicians to be sufficient. A National Institute of Health panel estimated that approximately 6,800 to 17,000 of home monitors are prescribed as a result of an apparently life-threatening episode in an infant (173). OTA has used 6,800 as the lower bound and 45,000 as the upper bound for an estimate of the number of medically necessary home apnea monitors in use and makes the simplifying as-

Table 8.—Basis for Estimate of the Number of Children Requiring Other Nutritional and Respiratory Support

Information source	Data	Implications	Comments
OASIS registry, Oley Foundation	147 children ages 0-10 in registry; 92 require parenteral nutrition	Ratio of enteral to parenteral nutrition is 1:1.67	Proportion of children also using respiratory support unknown; proportion of tube-fed population covered by registry unknown
Commercial registries	368 children in registry requiring enteral nutrition (i.e., tube feeding)	Ratio of enteral to parenteral nutrition is 1:1.01	Same as Oley Foundation registry
Hambrecht & Quist market analysis	7,500 persons in U.S. received home tube feeding in 1983	990 tube-fed children per year in the U.S. at home	Based on discharge data and sample of hospitals. Extrapolation assumes that 13.2% of tube-fed populaton are children (from commercial registry proportion)
Abbott Laboratories market analysis	5,500 persons in U.S. received home tube feeding in 1983	726 tube-fed children per year in the U.S. at home	Unknown basis for estimate. Same assumption of 13.2% children as above
California hospital discharge data for children	97 gastrostomy procedures, 15 closures in 1983	777 children tube-fed through gastrostomies each year	Of net addition to population of 82 gastrostomies, assumes each child received only one gastrostomy and required it for one year
State data:			
Illinois	36 children on Group III technologies served by home care program	2,445 Group III children per year in the U.S.	Ratio of ventilator: Group III children in program 22:36; apply this to extrapolation of 1,500 ventilator-dependent children in U.S. to yield total Group III estimate
Maryland	87 children in State requiring respiratory support; 61 require other than ventilators	3,513 children in the U.S. per year requiring respiratory support other than ventilators	Assumes Maryland identified the universe of such children in the State
Wisconsin	49 children served in State program require tube feeding; 49 require respiratory assist devices (other than ventilators)	2,401 U.S. children requiring tube feeding at any one point in time; up to 4,800 requiring respiratory support. Ratio of ventilator: Group III supports about 1:10	Presumably is an underestimate if not all similar children are served by State program. Probably considerable overlap between tube feeding and respiratory support groups. Prevalence of Group II probably overstated
North Carolina	8 hospitalized children in State with prolonged oxygen dependence (compared to 3 on ventilators)	Ratio of ventilator: oxygen support about 3:8	One-month survey, hospitalized children only
New Mexico	1 ventilator-dependent child; 18 other children requiring respiratory and nutritional support	Ratio of ventilator: Group III supports about 1:18	Prevalence of Group III probably overstated due to small number of ventilator-dependent children served

SOURCES: M.J. Aitken and L.A. Aday, *Home Care for the Chronically Ill and/or Disabled Technology Assisted Child: An Evaluation Model*, unpublished, November 1985; J. Bates, San Diego Children's Hospital, San Diego, CA, personal communication, July 1986; Blue Cross/Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicago, IL: Blue Cross/Blue Shield Association, January 1986); G. Cleverly, Human Services Department, Santa Fe, NM, personal communication, August 1986; L.L. Heaphey, The Oley Foundation, Albany, NY, personal communication, August 1986; E. Lis, Crippled Children's Services, Chicago, IL, personal communication, April 1986; Oley Foundation, Inc., "Nutritional Support and Hydration for Critically and Terminally Ill Elderly: Utilization in the Home," contract paper prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, September 1985; B.B. Rucker and K.A. Holmstedt, *Home Infusion Therapy Industry* (San Francisco, CA: Hambrecht & Quist, April 1984); and P. Tschumper, Department of Health and Social Services, Madison, WI, personal communication, April 1986.

Table 9.—Estimated Prevalence of Selected Chronic Conditions in Children, Age 0 to 20, 1983

Condition	Prevalence per 100,000 children, 1980	Approximate number of children in the United States, 1983
Mental retardation	2,500	1,781,300
Asthma (moderate and severe)	1,000	712,500
Diabetes mellitus	180	128,300
Congenital heart disease (severe)	50	35,600
Spina bifida	40	28,500
Sickle cell anemia	28	20,000
Cystic fibrosis	20	14,300
Hemophilia	15	10,700
Leukemia (acute lymphocytic leukemia)	11	7,800
Chronic renal failure	8	5,700
Muscular dystrophy	6	4,300
Traumatic brain injury	5	3,600

SOURCE: Prevalence rates from G.L. Gortmaker and W. Sappenfield, "Chronic Childhood Disorders: Prevalence and Impact," *Pediatric Clinics of North America* 31(1):3-18, February 1984. Population size estimates calculated by OTA based on prevalence rates and U.S. Census population data.

sumption that this range represents the number of monitors in use per year.

The minimum estimate of the number of children requiring renal dialysis is from Medicare End-Stage Renal Disease Program data. The Health Care Financing Administration, which administeres Medicare, documented 1,713 patients age 0 to 19 receiving dialysis in 1985 (110,166). Adding a minimum of 171 patients to this figure to account for patients age 20 to 21 (one-tenth, or 2 average age years, of the initial figure) and inflating the total figure by 3.6 percent per year (the increase documented from 1983 to 1984), yields a minimum of 2,022 children under age 22 on dialysis during 1987. This number underestimates the number of children requiring dialysis, since some are covered by private insurance. A maximum estimate assumes that all children with chronic renal failure require dialysis. The prevalence of this condition has been estimated at 8 per 100,000 children, or nearly 6,000 children under age 22 in the United States (see table 9).

There exist no appropriate data at all to estimate the number of children requiring other devices and associated nursing care such as urinary catheterization and colostomy care.[9] This group is very large; indeed, it may be larger than all other groups combined. If this group is included in the population of technology-dependent children, the size of that population will increase dramatically. Many children with spina bifida and other spinal conditions, for example, require urinary catheterization. The total number of children in this group could easily be 30,000 or more (see table 9).

If the definition of technology dependence used in this technical memorandum were not limited to children using medical devices, this group could potentially include a substantial proportion of children with hemophilia, insulin-dependent diabetes, and many other chronic diseases. While most such children require periodic injections of medications and a relatively modest amount of nursing care by family members, a few have more intensive needs for monitoring and nursing. It is only the lack of dependence on a major medical device, not necessarily a difference in nursing and care needs, that distinguishes this population from those children included in Group IV.

Table 9 presents prevalence estimates for several serious chronic illnesses in children. Unfortunately, no quantitative information on the level of technology and nursing needs for this or any other subpopulation of children with chronic illness exists. Some of these children have already been included in groups mentioned above; for example, children with cystic fibrosis, muscular dystrophy, traumatic brain injury, or severe asthma who meet the definition of technology dependence likely need respiratory or nutritional assistance and would be included in Groups I through III. Children with rheumatoid arthritis and leukemia would be included under Group II if they required periodic intravenous drug therapy.

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[9] Data from the National Center for Health Statistics, which surveys a large sample of hospital discharges every year, suggest that the annual incidence of colostomies and ileostomies in children may be a few thousand per year (172). The survey is not large enough to estimate an accurate number of these procedures for children, but it is certainly less than 10,000 per year and probably less than 5,000.

Wisconsin data illustrate how large the population of "technology-dependent" children could be if the definition did not require dependence on a device that compensates for a vital body function as a necessary criterion (but retained the "substantial nursing needs" criterion). Wisconsin operates a program that, among other criteria, enables children to receive certain health care benefits if they would be permanently institutionalized without these benefits and could be served less expensively at home. Of 181 children served by this program in mid-1986, one-third of the total required a very high level of care but did not require nutritional, respiratory, or other mechanical support.

What sources of information might be tapped in the future for more precise estimates of the number of technology-dependent children? One possibility might be a school-based survey, targeted at the population most likely to include a significant proportion of technology-dependent children—those children who have been individually assessed prior to educational placement. A similar approach is currently being used in an ongoing study to estimate more accurately the number of children with hemophilia, cystic fibrosis, and spina bifida (73). The approach is fraught with its own problems, not the least of which is that very young children and children living in hospitals or long-term care institutions would not be captured. Also, technology-dependent children are rare even among children assessed for possible special education placement.[10] A very large survey would be required to produce a reliable estimate of size of the population. Still, this source offers one possibility for estimating future apparent or real changes in the prevalence of technology dependence.

TRENDS IN THE POPULATION

Future changes in the size of the technology-dependent population will depend on three separate factors:

1. changes in the number of children who have the diseases and conditions that lead to technology dependence;
2. technological change, which can either increase the size of the population (if new technologies lead to increased survival dependent on long-term life-saving equipment), or decrease population size (if new technologies allow less intensive equipment and service needs, or prevent the development of disabling conditions); and
3. changes in medical practice and social attitudes, which are themselves affected by factors such as the emergence of new technologies and the availability of third-party payment.

General Trends in Chronic Illness and Disability

Trends in chronic illness and disability over time are somewhat difficult to identify. National surveys show that the proportion of children with reported major activity limitation has increased substantially in recent years, from approximately 1.1 percent in 1967 to the present 2 percent (124). However, this finding may be caused by any of a number of influences. Some of the apparent increase may be due to changes in survey methodology and in families' awareness of illness over time (123,124), rather than to real changes in disability rates. Another explanation is increased survival of children with certain chronic illnesses, such as cystic fibrosis and spina bifida. A third possible explanation is that new technologies and new systems of care, such as intensive care units for newborn infants, are resulting in more children who survive birth or trauma but with severe long-term disabilities. The absolute number of disabled and chronically ill children will increase as the children survive longer, even if the rates of onset of various disorders are unchanged.[11]

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[10] In Fairfax County, Virginia, for instance, 700 children were served in home or school-based special education preschool programs (ages 2 to 4) in August 1986 (14). Of these 700 children, 6 might have qualified as technology dependent (4 served in classrooms had tracheostomies or gastrostomies, and 2 served at home had special medical problems).

The number of children with inherited chronic diseases that can lead to technology dependence is unlikely to change significantly due to changes in the incidence of these disorders. Gortmaker and Sappenfeld conducted an extensive review of the literature in 1980 to investigate the prevalence of a number of common childhood chronic diseases (72). They noted that the incidence of most such diseases has been stable over time. It is now possible that new technologies permitting prenatal diagnosis of muscular dystrophy and cystic fibrosis may decrease the incidence of these diseases, if couples choose to terminate pregnancies when a fetus has been identified as having a genetic marker associated with the disorder. However, these prenatal diagnostic technologies are unlikely to have a major effect on overall incidence of chronic disease.

A more important factor affecting the number of children with chronic diseases, and one with implications for technology dependence, is the significant improvements in survival for children with many life-threatening diseases. Improvements over the past two decades in survival rates for children with leukemia, diabetes, certain heart defects, sickle-cell anemia, and chronic kidney disease have greatly increased the number of such children who live to adulthood (72). Better and more aggressive treatments for spina bifida and muscular dystrophy have also increased the survival of children with these disorders (35). Children with cystic fibrosis who would have died in early childhood two decades ago are now surviving, and over 50 percent of them live into adulthood (109). Long-term survival of children with intestinal malformations will greatly increase the total number of children requiring parenteral nutrition.

Changes in head and spinal cord injury rates, and changes in the survival of severe trauma patients, could affect the size of the population. More important, however, is the rising incidence of acquired immunodeficiency syndrome (AIDS). AIDS is likely to continue to spread in infants as it spreads in women, since the virus can be communicated from mother to fetus at or before birth (40). This disease is likely to increase the number of children receiving prolonged intravenous drug therapy, nutritional support, and considerable nursing care. A few hospitals have experienced dramatic increases in the number of babies with AIDS and in the number of those babies growing up in the hospital (22).

The most profound changes in the incidence and prevalence of disorders leading to technology dependence seem to be occurring in neonatal care. It has been widely asserted that the increased survival of very-low-birthweight (less than 1,500 g) infants, due to improved, aggressive neonatal intensive care, has resulted in a sharp surge in the number of ventilator- and other technology-dependent children. If this is true, continued advances towards survival of very-low-birthweight infants can be expected to increase the number of such children. If, on the other hand, technologies are successfully developed that can prevent prematurity or moderate the development of chronic lung disease in newborn infants, the number of infants on long-term ventilation and nutritional support may be considerably reduced.

Most medical evidence thus far supports the contention that the increased survival of very-low-birthweight infants has not increased overall rates of disability, but it may have increased the actual number of severely disabled children. A study of changes in infant morbidity and neonatal mortality between 1976 and 1978-79 found that neonatal mortality decreased by 18 percent during this time, while infant morbidity also decreased by 16 percent (144). Overall, therefore, newborn survival did not lead to an increase in long-term disability. However, the detected decrease in disability was among the minor disability categories; "the proportion of children with severe or moderate congenital anomalies or developmental delay did not change" (144). Other evidence supports three conclusions:

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[11] Evidence from public school records tends to support the premise that the number of children with severe disabilities, or at least the number being served by public schools, has increased. The proportion of multihandicapped children, for instance, increased from 0.12 to 0.16 percent of school enrollment between 1976-77 and 1982-83 (187). However, school data on disability is generally considered unreliable because of the greatly varying definitions different school districts use.

1. within groups of infants of a given birthweight, handicap rates remain stable or decrease over time;
2. handicap rates are greatest in the lowest birthweight groups; and
3. infants in the lowest birthweight groups are surviving in increasing numbers (162).

If the incidence of severe disorders is unchanged or even declines somewhat, but the total number of neonatal survivors increases, then the number of infants with severe disabilities increases overall. Box B describes a common source of respiratory disability in infants and the differing rates of incidence of this disorder in infants of different birthweights.

Future Changes Due to New Maintenance and Treatment Technologies

The most promising technologies to decrease the incidence of long-term technology-dependence are those aimed at preventing the need for long-term respiratory support in infants. Current efforts to combat chronic lung disease in newborns are described in box C. One or more of these technologies may eventually greatly reduce the number of infants with long-term technology dependence. However, significant changes are not likely to be apparent for a few years yet.

New technologies may have other direct effects on trends in the technology-dependent population, aside from their effects in reducing the underlying disorders that lead to technology dependence. For example, advances in implantable infusion pumps for long-term chemotherapy and implantable phrenic nerve pacers to stimulate breathing could reduce the constant, complex nursing needs associated with many technology-dependent children.

Enhanced access to transplant technology may either increase or decrease the number of children requiring intensive long-term nursing services. As the number of infants and children receiving bone, liver, heart, and other organ transplants grows due to increased transplant experience and enhanced insurance coverage, children recuperating from transplants may become a group for whom intensive home medical care is both socially and financially desirable. Access to intensive medical services in the home setting might allow these children to leave the hospital earlier than would otherwise be possible, and they may have ongoing nursing and technology needs. On the other hand, increased transplant success could obviate the need for very-long-term dependence on technologies such as insulin (through pancreas transplants), parenteral nutrition (through bowel transplants), and dialysis (through kidney transplants).

Changes in Medical Practice

The wide range of prevalence estimates for technology dependence suggests that medical practice patterns may vary considerably among regions, States, and medical centers. Some of these differences may be in simple treatment protocols. For example, there is some evidence that differences in medical practice can inadvertently affect the incidence of chronic lung disease in newborns. In an examination of treatments and rates of bronchopulmonary dysplasia in eight hospitals with regional neonatal intensive care units, Avery and colleagues found that the rates of this newborn chronic lung disorder varied considerably among centers, even after adjusting for differences in the newborn populations (11). They concluded that the differences in routine treatment practices among these centers were probably responsible for the differences in the rates of this disorder, implying that changes in the routine practices of hospitals with higher rates could reduce the incidence of dependence on long-term respiratory support.

Other researchers have documented the variation in routine treatment patterns among physicians treating people with fatal chronic diseases. A 1981 study demonstrated that positive-pressure ventilation may extend the lives of children and adults with muscular dystrophy by an average of 7 years (12). Only one-third of the patients in the study had tracheostomies. By comparison, in a 1985 survey of Muscular Dystrophy Association

Box B.—Bronchopulmonary Dysplasia

One of the most common sequelae of neonatal intensive care, and one with particular implications for technology dependence, is bronchopulmonary dysplasia (BPD). First recognized in the early 1960s (154), this condition sometimes occurs in infants requiring mechanical ventilation soon after birth. An infant with BPD is unable to be weaned from ventilation during the first month after birth due to certain changes in the lung that can often be detected by X-ray (71).

Pneumonia, meconium aspiration, patent ductus arteriosus, and apnea of prematurity are among the many conditions that can lead to the initial need for assisted ventilation (and, thus, sometimes BPD) in newborns (71). The most common reason for initial ventilation, however, is respiratory distress syndrome. This syndrome, characterized in its initial stages by an increasing need for oxygen, is often experienced by very premature infants because an essential lining layer in the lung (pulmonary surfactant) has not yet developed (99).

Table 10 presents estimates of the annual incidence of BPD by birthweight category. There are no nationally representative data on the incidence of BPD. A multi-center study of 700 to 1,500 g babies in 1983 and 1984 found that one-third of the survivors had chronic lung disease (11). OTA used this 33 percent estimate for very-low-birthweight infants, although other researchers reported rates of BPD incidence among their institutional populations varying from 25 to 75 percent of respiratory distress syndrome survivors under 800 g at birth, and from 13 to 62 percent of survivors weighing less than 1,000 g at birth (17,25,45,74,85,138).

Researchers have not reported in the literature on BPD incidence among the larger low-birthweight infants, but the authors of a recent review article about BPD estimated its incidence at 10 to 20 percent among infants with RDS who receive mechanical ventilation and survive (71). OTA adopted the low end of this estimate, 10 percent, in calculating the BPD incidence among babies weighing 1,501 to 2,500 g.

Only a relatively small proportion of the babies developing BPD are obvious candidates for technology-dependent home care. In their eight-center study, Avery and colleagues found that about 4 percent of infants weighing less than 1,500 g at birth still needed supplemental oxygen at 3 months of age (although the range among institutions was considerable) (11). BPD can take mild, moderate, or severe forms, and infants are weaned from the ventilators and/or oxygen support after variable periods of time.

In the future, the incidence of BPD will likely decline, although extremely low-birthweight babies susceptible to BPD—including babies weighing less than 500 g at birth—are increasingly surviving (162). Refinements of existing techniques and newly introduced neonatal technologies might substantially reduce BPD in premature infants within a few years.

Table 10.—Estimated Incidence of Bronchopulmonary Dysplasia, 1984

Birthweight (grams)	U.S. births (1984)	U.S. neonatal mortality (1980)	Neonatal survivors	Percent survivors with BPD	Total infants with BPD per year
500-1,500g	39,045	43.1%	22,217	33%	7,332
1,501-2,500g	202,806	2.4%	197,743	1%[a]	1,977
				Total	9,309

[a] Goldberg and Bancalari (71) estimate that approximately 10 percent of infants with respiratory distress syndrome (RDS) get BPD. If approximately 10 percent of all surviving infants get RDS (174), then approximately 1 percent of all survivors get BPD.

SOURCE: Office of Technology Assessment, 1987. Numbers of U.S. births from U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, "Advance Report of Final Natality Statistics, 1984, Table 24," *Vital Statistics Report* 35 (4, supp.):July 18, 1986. Neonatal mortality rates from U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, "National Infant Mortality Surveillance (NIMS)," unpublished tables, May 1986. BPD incidence rates approximated from M.E. Avery, Boston Children's Hospital, Boston, MA, personal communication, July 23, 1986; and ranges presented in J.D. Horbar, "A Multicenter Survey of 28 Day Survival and Supplemental Oxygen Administration in Infants 701-1500 Grams," paper presented at the Ross Laboratories Special Conference on Topics on Neonatality, Washington, DC, Dec. 7-9, 1986.

Box C.—Changing Technology in the Neonatal Intensive Care Unit

Preventing the complications of mechanical ventilation in newborns has been a focus of research for some time. Changes in the way artificial ventilation is administered to newborns have been an important part of that research (71,153). However, medical practices and the use of technology still vary widely among perinatal centers. Avery and her colleagues surveyed eight centers in 1983 and 1984 for their experience with chronic lung disease in infants weighing 700 to 1,500 g. The researchers found that some institutions did significantly better than others, and that routine management techniques used for the very small infants might explain the differences (11). Refinements in existing techniques may thus hold promise for reducing the development of bronchopulmonary dysplasia (BPD) in ventilated infants in the future. Some new technologies, such as the high frequency ventilator (which delivers multiple small breaths instead of slower, larger ones) and extracorporeal membrane oxygenation (essentially a heart-lung machine for newborns with severe asphyxia), may also have some effect.

Other technologies under investigation focus on preventing respiratory distress syndrome (RDS), the precurser of BPD in most infants. The administration of steroids to mothers in preterm labor in order to accelerate infant lung maturation has been used and studied for 16 years (9), but concerns about the long-term effects of the therapy have prevented its routine use (43). Recent large-scale studies are somewhat contradictory but suggest that the technology can reduce the incidence and severity of RDS, and may improve survival in some very premature infants, with no evidence of negative long-term effects (43,174). Even if antenatal steroid therapy does become generally accepted as useful, however, it will have several limitations. It clearly does not work for all babies. And in addition, because the therapy must be initiated at least 24 hours before delivery in order to be effective, many women in preterm labor cannot be candidates for its use.

Treating surfactant deficiency by administering artificial or natural (animal lung) surfactant to the lungs of very premature babies at or soon after birth has the potential to greatly reduce the incidence of severe RDS. The basic chemistry of lung surfactant has been known for a long time, but research is ongoing regarding the best mixture, the optimum dose, and the timing and frequency of administration. At least five recent clinical trials testing natural surfactants document that surfactant-treated infants have less severe RDS (and, presumably, less likelihood of developing BPD) than control infants (66,89,100). Studies with artificially produced surfactant, on the other hand, have shown essentially no benefit to respiratory function (76,183).

Large-scale, multi-center trials are being undertaken in Europe, Japan, and the United States to continue to test surfactant experimentally. It is possible that surfactant therapy could become generally available for preterm babies within 2 to 5 years (10,143).

clinics around the country, 43 percent of ventilated patients were found to have permanent tracheostomies (35). This difference may represent an increasing willingness over time to treat end-stage muscular dystrophy patients aggressively.

The 1985 clinic survey also revealed that 24 percent of the responding physicians did not provide respiratory support systems to individuals with degenerative neuromuscular disorders, while 33 percent prescribed such supports routinely and the remaining 42 percent provided them only under specialized circumstances (35). The researchers found no standard patient-selection processes or established protocols for respirator use. If all physicians applied the same criteria for ventilatory support as those physicians who prescribe this treatment routinely, the number of people with end-stage muscular dystrophy using mechanical ventilation could triple.

Other differences in medical practice and social attitudes may also be reflected in rates of technology dependence. Some centers now treat newborns weighing less than 500 g (1.1 lbs) aggressively, although these babies are highly unlikely to survive (74). The promulgation of "Baby Doe" regulations and accompanying social attitudes has probably had at least some marginal influence on physicians' decisions to treat severely premature or disabled infants aggressively in the United States (145). It is likely that the trend toward aggressive treatment of very small newborn babies will continue, at least in the short term.

Whatever the reasons, differences among medical centers and geographic areas do exist. As has been noted by one clinician, "There are some centers that just don't seem to have children that require home ventilation" (91). Whether this difference is due to more aggressive attempts to wean ventilated children in those centers, or other factors that result in fewer infants who both survive and require long-term ventilation, is unclear.

Finally, improved access to funding for nonhospital long-term care, particularly home care, could result in more technology-dependent children and their more visible participation in society. It is possible that providing opportunities for children to be in home or home-like settings, combined with enhanced funding for long-term care, eliminates some of the social, financial, and medical disincentives to initiate and maintain long-term technology dependence. The three States with the highest identified prevalences of ventilator-dependent children all have aggressive home care programs to serve such children; North Carolina, a State with few ventilator-dependent children, does not. More families may consider it worthwhile to maintain the life of a terminally ill child as long as possible if they can afford to take the child home, and more physicians may consider it appropriate medical care to prescribe long-term ventilation for children.

CONCLUSIONS

Defining the population of technology-dependent children is a necessary first step for both enumerating the population and providing health care benefits directed at this population. That arriving at such a definition is not easy is clear from the fact that, after 5 years of public debate about the issue, no satisfactory definition exists. From a clinical perspective, the crucial distinguishing characteristic of these children is that they require special equipment and an intense level of medical services that are beyond the normal capabilities of untrained families. From an insurance program perspective, the crucial characteristic of these children is that it may be possible to care for them more appropriately and less expensively at home if the funding and services are made available. Although the two populations described by each of these characteristics overlap considerably, in that both require some form of hospital care if services in other settings are unavailable or unaffordable, they are not identical.

OTA's estimates of the size of the medically stable, technology-dependent child population at any one point in time, based on available sources of data for four alternative groups, are as follows:

1. Approximately 680 to 2,000 children per year in the United States are substantially or completely dependent on mechanical ventilation.
2. Approximately 600 to 9,000 children require intravenous therapy each year, including 350 to 700 children dependent on intravenous nutrition.
3. Approximately 1,000 to 6,000 children are dependent on some other kind of device-based respiratory or nutritional support, such as suctioning, tracheostomy care, oxygen, or tube feeding. **The cumulative number of children in the above three groups is between approximately 2,300 and 17,000 technology-dependent children per year.**
4. Expanding the definition of technology-dependent children to include children requiring apnea monitors and kidney dialysis would increase the size of the technology-dependent child population to between approximately 11,000 and 68,000 children per year. Adding children requiring urinary catheterization and colostomy/ileostomy care to this population could raise the upper bound of this estimate to as high as 100,000 children.

There is no evidence of overall increase in the incidence of most severe chronic disabling conditions. However, the number of technology-dependent children appears to have been increasing over the past ten years, due primarily to increased survival of very-low-birthweight infants, who have a high incidence of chronic lung disease, and increased survival of children with certain inherited and congenital chronic disorders, particularly cystic fibrosis, muscular dystrophy, and congenital anomalies. AIDS is also increasing the technology-dependent population. This trend is likely to continue for several years. In the long run, it is not clear whether the trend will continue, level off, or represent a "bump," analogous to the polio and rubella epidemics that produced many severely disabled children earlier this century.

Factors that may *increase* the size of the population include:

- wider acceptance of medical practices such as aggressive treatment of individuals with end-stage disease, severe trauma, and severe newborn disabilities; and less aggressive attempts to wean ventilated children;
- consequent increased survival of children with conditions that would be fatal if not aggressively treated, and are highly likely to result in technology dependence if they are treated;
- new severe chronic diseases, such as AIDS;
- lessened acceptance of abortion;
- sufficient financing to encourage aggressive medical practices;
- technologies that improve survival outcomes for burn patients or transplant patients, but at the cost of extended recuperative care; and
- increases in the apparent size of the existing population due to new opportunities to obtain funding for home care.

Factors that may *decrease* the size of the population include:

- improved prenatal diagnostic tests for severe, chronic disease;
- technologies that can prevent trauma (accident prevention), premature births (prenatal care), and specific neonatal disorders;
- technologies that can lessen the intensity or duration of technology dependence, such as oral insulin or transplants to correct diabetes; and
- increased acceptance of palliative care for fatal disorders.

It is likely that the expansion of current medical practices tending to increase the size of the technology-dependent population will continue in the short run, perhaps for a decade or longer. Thus, the population size estimates given in this chapter will probably be lower than the actual population size within a short time. In the longer term, opposing factors—most significantly, technologies to prevent premature birth or its complications—may eventually lead to stabilization or even a decrease in the technology-dependent population.

Chapter 3

Comparing Effectiveness and Costs of Home v. Hospital Care

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INTRODUCTION

The purpose of this chapter is, first, to summarize existing evidence on the effectiveness of home care for technology-dependent children and the components that may affect it. Second, the chapter presents evidence regarding the costs of home v. hospital inpatient care. More discussion of alternative settings of care can be found in appendix D.

EFFECTIVENESS

Evidence of the Effectiveness of Home Care

There is a broad assumption in the home care literature that, compared to institutional care, home care is both more desirable and more effective in promoting the mental, emotional, and physical health of children. This assumption seems a reasonable one for many, perhaps most, technology-dependent children. There is little reason to believe that when a family wants its child at home, and adequate medical services and support are available, the home is not an effective setting of care.

Unfortunately, concrete evidence on how much more effective home care is, or the circumstances under which it is as effective, is lacking. There is also virtually no evidence in the literature on the relative effects, either medical or psychological, of care across various alternative settings for the technology-dependent population, including alternatives such as board and care homes.

A few studies have attempted to document the beneficial effects generally ascribed to pediatric home health care, or to special services associated with this care. The largest and most rigorously designed of these studies was performed as part of an evaluation of the Pediatric Home Care (PHC) unit at the Albert Einstein College of Medicine-Bronx Municipal Hospital in Bronx, New York (150). In that evaluation, chronically ill children were randomly assigned either to the PHC unit or to standard outpatient clinic-based care (with no special services). Standard inpatient care was not compared. PHC services included delivery of health services, patient and family training, service coordination, and patient advocacy. Services were delivered by an interdisciplinary team whose core was the pediatrician, pediatric nurse practitioner, and family, but which also included physician specialists, a psychiatrist, a social worker, and a physical therapist.

Children enrolled in the PHC program had better psychological adjustment, families reported significantly higher satisfaction with care, and mothers showed reduced psychiatric symptoms compared to the control group (150). There was no difference between the experimental and control groups in the impact on the child's functional status, or in the impact of the child's illness on the family. The researchers in this study hypothesized that the social and psychological support offered by the program balanced the family's burden of caring for the child at home, resulting in no change in net impact on family activities, structure, or burden.

An evaluation of the impact of the home care coordination and support programs for ventilator-dependent children in three States (Louisiana, Illinois, and Maryland) is currently being conducted by researchers at the University of Chicago (3). Results from this evaluation are expected in late 1987.

Numerous parents and clinicians have asserted for some time that home care is superior to hospital care for medically stable, technology-dependent children. Children cared for in the home are believed to make faster medical and developmental progress, and have better psychosocial development, than children in the hospital (69,95,141,156). There are no published objective investigations of this hypothesis. It is a difficult one to test, since one cannot compare a child's progress at home with his or her progress in the hospital during the same time period.

The rate of chronic rehospitalization of children placed in family homes can be considered a measure of effectiveness of home care. It is to be expected that technology-dependent children will have occasional brief hospitalizations for acute episodes of infections and illnesses and for evaluation, but the ability of a program to reduce or eliminate avoidable rehospitalizations and emergency room visits could be a useful measure of its effectiveness.

Factors Influencing the Quality and Effectiveness of Home Care

Two sets of factors influence the effectiveness of home care: those internal to the home environment, including parental abilities and attitudes; and those external to the home, such as the availability of trained professional nurses and the quality of equipment available.

Internal Factors

A crucial condition for effective home care is that the family wants the child at home, and that it is *willing* and *able* to help care for the child (1) or to accept and support a professional, full-time caregiver into the household. Parents have expressed strong desires to have their child at home, and they commonly take over much of the child's nursing needs (60,156). They may become so proficient in providing the necessary nursing that they train some of the the professionals who assist in their child's care (156).

However, there are families for whom full-time long-term home care may not be the best alternative for either the child or the family. The families of chronically ill children can sometimes encounter severe and ongoing psychological and emotional stress (54,173,180). Some families may be simply unable or unwilling, for physical, psychological, or financial reasons, to cope with intensive home care for the child. Other families might want to have the child at home, but might need a long adjustment period, or might need to feel confident that respite or long-term care outside the home is available if the stress becomes too great. In a few cases, a parent might be willing to care for a child but be unable to do so safely. These factors lead to less effective home care and the need for alternative settings of care.

External Factors

The availability of services in various settings is also crucial to the quality and effectiveness of home care relative to institutional care. Home care may not be more effective than hospital or other institutional care if the appropriate range of services are not provided. If a child can receive therapy or other vital services in the hospital but not at home due to lack of insurance coverage, home care is likely to be relatively ineffective. Conversely, if a child receives more intense, individualized therapy and education at home, home care is likely to be more effective than hospital care.

Professional nursing skills are a particularly important factor in the effectiveness of care, but skilled nurses are not always available for home care. In an acute-care hospital, nursing services for a technology-dependent child are most likely to be provided by a registered nurse (RN), and often by an RN with extensive training in pediatrics or intensive care. In home settings, on the other hand, professional nursing is much more variable. Some home care agencies specialize in "high-technology" home care or pediatric home care. Others, however, may not have nurses (whatever their certification level) trained to provide the specialized care needed by technology-dependent children. Most licensed practical nurses (LPNs) and many RNs, for example, are not trained to operate ventilators and provide respiratory care.

Third-party payers may place restrictions on the services that a nurse with a particular set of credentials can provide, although there is considerable controversy over the relationship between credentials and quality of care. In New Mexico's Medicaid program, for example, RNs may provide any respiratory- or nutritional-support home care; LPNs can provide most such care, but not ventilator-related care or parenteral nutrition; and paraprofessional attendants may not provide any such complex care (34). In Louisiana, on the other hand, families needing assistance at home rely heavily on trained paraprofessionals even for ventilator-related care (97). These different conventions are associated with differences in service availability, but they also reflect different implicit evaluations of the relationship between credentials and quality. The differences in the quality of home care provided by family members, paraprofessionals, LPNs, RNs, and specialty nurses has not been addressed explicitly in the literature. Undoubtedly, the level of skill-specific training is an important variable, regardless of the general certification of the provider.

Certain quality issues arise at home that rarely arise in the hospital because of established routines or protocols in the latter, but not the former, setting. For example, home chemotherapy introduces substantial concerns regarding the use and disposal of very toxic chemicals (87). Widespread use of and dependence on home ventilators introduces concerns regarding the quality of maintenance of equipment and issues of how the widely dispersed users are informed about potential mechanical defects (118).

Concerns about monitoring the quality of home health care have been raised before (160). These concerns are particularly relevant in the context of widespread emphasis on early hospital discharge. In a number of States, Medicaid pays hospitals a preset rate per discharge regardless of the actual length of hospital stay of a child (101). Once home care for technology-dependent children is widely accepted in an area, and funding becomes available, hospitals may be very reluctant to keep these children, whose length of stay is generally quite long. If the third-party payer's interests also lie in encouraging home care, parents could be forced to take a child home, possibly with insufficient services, before they are adequately prepared. Or, parents could be forced into home care when they are unable and unwilling to provide the service at all. Anecdotal reports suggest that, in some cases where home care is a funded option, hospitals or payers are indeed putting pressure on families to take these children when the families are not ready to do so (104,120). These circumstances could have serious negative implications for the quality of home care.

COST

Cost considerations have played a substantial role in the evolution of home care for technology-dependent children. When the Federal Government first waived certain Medicaid rules to permit hospital-bound, technology-dependent children to receive Medicaid payment for equivalent home services, it did so on two grounds: that the home was equal or preferable to the hospital as a setting for a child's care and development, and that home care would be a fraction of the cost of hospital care to Medicaid. These criteria, and particularly the second, have endured. From 1981, when the first exception was granted, to 1986, Medicaid (and other third-party payers) has continued to require a showing of program cost savings before paying for home care for many technology-dependent children. Of course, program cost savings and social cost savings are not necessarily the same.

This section first describes the components of home care costs—i.e., the factors that influence the costs of home care for different technology-dependent children. It then presents the issues and problems involved in comparing the costs of care across alternative settings. Finally, it presents existing evidence from the literature and from home care programs regarding comparative average total costs of technology-dependent children across settings.

Components of Home Care Costs

Startup Costs

Startup costs are one-time costs that are usually incurred before the child is placed in the home. They include the costs of home improvements, major equipment, and caregiver training.

Home improvements are often a necessary prerequisite to home care, particularly for ventilator-dependent children. Home modification needs can include:

- wiring and other electrical work;
- construction (storage and preparation[1] space, wheelchair ramps, equipment accommodation);
- special needs (e.g., a generator for emergency power in rural areas) (178); and
- general upgrading that requires the family to move (e.g., moving from an unsanitary apartment or one inaccessible to a wheelchair to other housing where appropriate modifications can be made).

The costs of necessary home modifications can vary substantially; in the first 3 years of Louisiana's home care program for ventilator-dependent children, home modification charges ranged from $0 to $13,500 (97).

Equipment can be a major component of startup costs, particularly for children on ventilators or oxygen. (If the child is not expected to be technology-dependent at home for long, or if an insurer will only pay for rented equipment, much of the child's equipment will be rented rather than purchased.) Special equipment for a ventilator-dependent child might include two ventilators (a primary and a backup ventilator), an emergency battery, an oxygen tank, a suction machine, a nebulizer (to deliver aerosol medication), a manual resuscitator, and an infusion pump (to control the administration of nutrients). The child may also need other supportive equipment such as a wheelchair, a commode, a special bed, and various other adaptive furniture and devices. A child dependent on intravenous feeding, by comparison, might have startup equipment costs that are a negligible proportion of total home costs.

Training in the necessary medical procedures, which may take days or weeks, is a vital first step for families. Even if they will have professional nursing help, they must learn to perform the necessary procedures as a guard against emergencies (e.g., resuscitation) or in situations where the regular nurse might be incapacitated or absent. Table 11 shows a list of skills the family of a child on respiratory support or infusion therapy (intravenous drugs or parenteral or enteral nutrition) might need to learn.

Training time and costs differ by training institution, by level of care the child requires, and by the family members' ability to assimilate information and perform the necessary tasks. Institutions training families in respiratory care may do this in several days of intensive training (13). Or, they may gradually encourage family members to provide care while the child is in the hospital, perhaps requiring that the family provide total care for 48 hours before discharge (57,65). Training in intravenous techniques can also be time-consuming; one program reported a 3-week training period for home patients (181).

Ongoing Supplies and Services

Supplies are often purchased monthly through the hospital or home care agency. Table 12 details the supplies needed for intravenous therapy and tube feeding. The highest ongoing supply costs are probably incurred by children requiring total parenteral nutrition, because their nutrient formulas—consisting of "pre-digested" fat, carbohydrate, and protein solutions—are individualized, require special handling and storing, and have expensive components. In a 1982 survey, average charges for nutrition supplies and solutions were reported as $3,059 per month for hospital-supplied solutions and $4,615 per month for nonhospital-supplied (possibly pre-mixed) solutions (122). The range of charges, however, was very wide; the highest charges were nearly double the average in both categories.

Ventilator-dependent children also have high ongoing supply costs. As is shown by the child

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[1] Extra space may be needed, for instance, for preparing nutrient solutions or for cleaning and sterilizing equipment.

Table 11.—Checklist of Respiratory and Infusion Skills for Home Care Patients and Families

Respiratory skills:

1. The disease process:
   - lung disease and its treatment
   - short- and long-term prognosis and goals
2. Pulmonary hygiene measures:
   - avoidance of infection (hand-washing and sterile technique)
   - adequate systemic hydration
   - chest physiotherapy procedure
   - sterile suctioning procedures
   - tracheostomy care procedure
   - tracheostomy tube cuff care procedure
   - signs of airway infection and cor pulmonae that should be reported to the doctor
3. Use and maintenance of the equipment:
   - daily maintenance of the ventilator
   - oxygen use, abuse, and hazards
   - cleaning and changing of ventilator circuits
   - resuscitation bag use and cleaning
   - suction machine use and cleaning
4. Nutrition counseling:[a]
   - maintenance of ideal body weight
   - special dietary restrictions as needed
5. Physical therapy:
   - ambulation, where possible
   - general strengthening exercises
   - relaxation exercises
6. Educational and diversional activities:
   - encouraging child self-care
   - sedentary activities
7. Access to services:
   - nurses
   - physicians
   - respiratory equipment suppliers
   - therapists
   - emergency power
   - other services

Infusion skills:[b]

1. Understanding of components of home infusion therapy:
2. Sterile procedures:
   - caring for medications and solutions
   - preparing medications and solutions for infusion
3. Infusion techniques:
   - measuring components, using syringes, bottles, and bags
   - setting up the infusion
   - starting the infusion
   - discontinuing the infusion
   - operating the infusion pump
4. Recognizing complications:
   - of the catheter
   - of the infusion
   - of the medications

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[a] This table is based on one for adults. Most infants on ventilators require enteral tube feeding for at least the beginning weeks or months. Thus, the families of these children must also be trained in infusion skills relating to tube feeding and care.

[b] Not all skills are applicable to all kinds of infusion therapy.

SOURCES: List of respiratory skills adapted from J. Feldman and P.G. Tuteur, "Mechanical Ventilation: From Hospital Intensive Care to Home," *Heart & Lung* 11(2)162-165, March-April 1982. Infusion skills adapted from Blue Cross and Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicago, IL: BC/BSA, January 1986).

Table 12.—Supplies Needed for Four Home Infusion Therapies

	Therapies for which supplies are needed			
Supplies	Parenteral nutrition	Enteral nutrition	Intravenous antibiotics	Chemotherapy
Intravenous catheter	X		X	X
Intravenous tubing	X		X	X
Medications	X		X	X
Nutrient solutions (e.g., lipids)	X			
Intravenous solutions (dextrose or saline)	X		X	X
Infusion pumps	X	X	X	X
Heparin lock and dilute solution	X		X	X
Needles and syringes	X		X	X
Dressings (gauze and tape or transparent	X	X	X	X
Nasogastric, gastrostomy, jejunostomy tubes		X		
Enteral bag and tubing		X		
Enteral feeding preparations		X		

SOURCE: Blue Cross and Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicago, IL: BC/BSA, January 1986).

whose reimbursable expenses are detailed in table 13, monthly costs for major supplies may total over $1,600 (116). Medications, special nutrient solutions, and equipment maintenance can add substantially to this cost.[2]

Nursing needs are highly varied and, for many children, are the most expensive component of home costs. Outlays for nursing care are inversely related to the amount of unpaid care that the family is willing and able to provide. As has been noted (148), most of the reduction in charges reported for ventilator-dependent patients at home results from shifting the burden of nursing costs from the payer to the family. Similarly, a significant part of the reduction in home charges observed by numerous intravenous therapy programs (96,130,132,151) is due to the fact that the patients in these programs receive little or no professional nursing at home.

Table 13.—Sample Home Respiratory Care Costs That Were Reimbursed by a Third-Party Payer, 1985

One-time purchase of equipment	Unit cost
Suction equipment	$ 714.29
Manual resuscitator	157.31
Emergency 12V battery	70.00
Heating nebulizer	324.00
Total one-time cost	$ 1,265.60
Monthly services and supplies	Monthly cost
Home assistance:	
Nursing	$ 7,320.00
Rentals:	
Backup ventilator	200.00
Ventilator	450.00
Suction device	50.00
Apnea monitor	200.00
Oxygen system	130.00
Supplies:	
Ventilator tubing	100.00
Oxygen masks	55.20
Liquid oxygen	816.00
Nebulizer	123.60
Sterile water	79.50
Tracheostomy tubes	143.70
Suction catheter w/ gloves	315.00
Cardiac leads	10.00
Total monthly cost	$9,993.00

SOURCE: M. Mikol, SKIP of New York, Inc., New York, NY, personal communication, June 1986.

Actual nursing care expenditures for a technology-dependent child depend on three factors: the complexity of care required, the amount of paid nursing care required (e.g., 3 hours per day v. 24 hours per day), and the certification level of the nurse. In general, 24-hour ventilator-dependent children with tracheostomies need the most constant and complex nursing care. Other children, such as those receiving intravenous nutrition or therapies, may need complex or intensive care for several specified hours per day; or they may need less complex care but need it constantly in order to avoid a life-threatening event (e.g., children requiring trachea suctioning).

Professional home nursing costs can be substantial and vary considerably with the certification level of the nurse. In New Mexico, for example, Medicaid pays $17 per hour for RNs and $13 per hour for LPNs, slightly more than the charges of the lowest priced home nursing agency in that State (34). If all care were provided by professional nurses, the monthly Medicaid payments for a child requiring an 8-hour professional nurse would range from $3,120 to $4,080; payments for a 24-hour nurse would range from $9,360 to $12,240. If Medicaid paid agency charges, as some insurers do, payments could be as high as $18,000 per month for a 24-hour RN.

Other factors can also affect nursing costs. For example, the need for an escort to accompany a nurse to work in a high-crime area would raise costs. Or, nurses might demand higher pay when working in such areas.

Specialized therapy is needed by most technology-dependent children in order to progress. Speech therapy, physical therapy, and occupational therapy are commonly provided to these children in one or more weekly visits. Basic respiratory therapy, however, often becomes a required skill of the primary caregiver, both because it is often required so frequently and because many third-party payers do not pay for home respiratory therapy visits.

Outpatient services to technology-dependent children in home care can include regular visits to one or more specialty physicians (e.g., a pediatric pulmonologist), frequent laboratory workups, and visits to a local pediatrician or family physician who oversees the child's "well child care." A local physician who is familiar with the child's health status and medical needs is particularly important for families who live a great distance from the specialty clinic or tertiary care hospital. Even with these outpatient visits, children in home care may have frequent hospitalizations for in-depth assessment, initiating new treatments, respite care, or complications or sudden emergencies relating to their conditions. These rehospitalizations are often overlooked when comparing home and institutional care costs.

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[2] Inadequate or poorly coordinated equipment maintenance can present a major problem to a home care program and a significant expense to families or third-party payers (104). Programs are still accumulating experience in working with manufacturers and suppliers to minimize problems.

Although outpatient visits and laboratory tests are often relatively minor compared with other home care costs, they are ongoing and by no means negligible. For example, the individuals included in a 1982 survey of home parenteral nutrition programs averaged $23 to $32 per month in physician and clinic costs (for patients served by hospital- and nonhospital-programs, respectively), with extremes ranging from $6 to $83 (122). Laboratory work for stable patients in this survey averaged $69 and $82 per month for hospital- and nonhospital-supplied patients, respectively, and ranged from $4 to $350 per month (122).

Transportation to outpatient services and to school is required by technology-dependent children in home care and can be a substantial cost for some children. Children receiving intravenous antibiotic therapy or chemotherapy may require physician visits as often as twice a week (130). For stable ventilator-dependent children, visits may be less frequent—weekly or monthly—but transporation costs may be very high because the transportation vehicle must be spacious enough to accommodate respiratory equipment and a wheelchair. Children served by the Louisiana home program for ventilator-dependent children travel up to 385 miles round-trip for physician and clinic visits (97). Of 23 children whose transportation needs were detailed by this program as of June 1985, 7 used the family car; 3 used special vans purchased for that purpose; 3 used public transportation; 1 child used an institutional van; and 8 children used ambulances.[3]

Respite care is care that gives the family some relief from ongoing nursing care. It may be in the form of an occasional professional nurse or other person who provides care in the home. Or, it may be in the form of a nearby hospital or other facility that cares for the child while the family is on vacation or pursuing other activities. Respite care raises the immediate costs of home care, but it may lower total costs if the assurance of occasional respite enables the family to provide most ongoing care.

Case management—coordination and oversight of the package of services provided to an individual—is a vital service to most technology-dependent children because of the multiplicity of startup and ongoing services needed. Case management may be performed by a health care professional, such as the child's pediatrician (112) or a specially trained pediatric nurse (129). Or, third-party payers may provide case managers (as part of an individual benefits management program) to ensure, first, that the appropriate mix of services are available to enable the child to receive appropriate care at home; second, that those services continue to be provided as arranged; and third, that the child's progress is monitored, so that appropriate changes in service are made.

Case management can sometimes minimize the costs of care for children already being cared for at home. The Florida "Rural Efforts to Assist Children at Home" (REACH) program, a Medicaid demonstration project, succeeded in reducing rehospitalizations and emergency room visits of chronically ill children in that program as compared to equivalent children not served by the program (129). The program, targeted at high-cost children (not necessarily technology-dependent children) eligible for both Medicaid and Services to Children with Special Health Care Needs, used community-based pediatric nurses as case managers, coordinators, and consultants to help families make the most appropriate use of medical services (129).

The most important aspect of case management is that it can serve both the interests of the family and of the third-party payer. At present, it is closely linked with the expectation of cost savings, and the process of ensuring those savings. If a private insurer expects to eventually pay out the maximum lifetime benefit, however, the incentive to provide case management may be weakened. There is also a danger that case management will be superficial. Managers whose activities are limited by the payer's interests, or by a large caseload, may be hampered by not being intimately acquainted with the child's needs, or by ignorance of important resources that could be made available.

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[3] Three of the children using ambulances did so for emergency or interhospital transfer purposes only, while they resided in institutions or nursing homes. One other child required an ambulance twice for tracheostomy tube changes. Of the remaining 4 children using ambulances for transportation, 3 eventually died. No other forms of transportation are recorded for any of these 8 children.

Issues in Comparing the Costs of Hospital and Home Care

1. **Cost to whom?**—The relative costs of hospital and home care depend on whether one is considering costs to Medicaid, costs to private insurers, costs to the family, or total resource costs. Home care might often involve fewer total resource costs than hospital care, but it might not cost the third-party payer less. For example, in some States, Medicaid pays hospitals a set rate per patient or per admission, regardless of the actual length of stay for that patient or the services provided. In these States, paying for adequate home care for technology-dependent children could cost the State and the Federal Government more than financing those children's care in a hospital at the fixed rate. (Of course, the uncompensated costs to the hospital caring for children in this situation are very high.)

Home costs may be lower to third-party payers than institutional costs because of certain uncompensated costs incurred by the family when the child lives at home. The two most notable examples of such uncompensated costs are the costs of basic room and board, and the unpaid time of parents or other volunteer caregivers.

For some children, paid home services may be replacing not institutional care but care previously provided by the family at great expense. These services reduce the costs to the family while increasing the net cost to the third-party payer.

2. **Comparing equivalent costs.**—Different sources of information on costs of technology-dependent children use different concepts of cost. For example, one may report hospital charges, while another reports third-party payments to the hospital. Hospital charges themselves may not be equal to the actual costs associated with providing a service. For example, one analysis of intensive care unit (ICU) services found that the charges in one hospital for room and board in the ICU were only slightly more than one-half of calculated actual costs to the hospital (77a). Even comparing average hospital charges (say, per month) with average home care charges for a technology-dependent child can be misleading if the two include different services. For example, hospital charges often include acute-care services such as surgery, while home charges do not. Inconsistency in comparing the appropriate equivalent costs (i.e., maintenance and recuperative treatment costs) in each setting is a major problem in the literature.

3. **Biased sources of data.**—Most third-party payers offering intensive home care services require that it be cheaper for them to pay for care in this setting. Consequently, most data on technology-dependent children served at home will, by definition, show that home care is cheaper. There may be some children who are not discharged home because it will not be cheaper to the payer, but since these children are not served at home their presumably higher home costs are not recorded.

4. **Different costs for different children.**—In the hospital, costs depend largely on medical need and on the physician's judgment and style of medical practice. At home, however, the costs of care vary not only with the type and severity of disability, but also with the family and home environment. Factors such as the ability of family members to provide most nursing care, and the extent of home care renovations needed, have great impact on costs of home care.

5. **Cost in which setting?**—Given sufficient equipment and services, many technology-dependent children could, if necessary, receive care in any of a number of settings that are intermediate between the acute-care hospital and home (see app. D). In some urban areas, several of these intermediate options may actually be available; in other areas, none may be. Thus, while for one child it may be appropriate to consider the relative costs and effectiveness of care in a long-term rehabilitation hospital as well as home and acute-care hospital costs, for another child the rehabilitation hospital may be unavailable, even if it theoretically offers the lowest cost care.

The primary reason for variations in average cost across institutional settings is that different settings offer a different mix of services and different levels of service intensity. For example, one setting may cost more because it offers full-time respiratory therapists on staff. However, cost is not a direct measure of effectiveness or services. Costs and effectiveness are related (e.g., adding home services to enhance effectiveness may increase costs), but, given no other information, one cannot deduce the relative effectiveness of different settings from their relative costs.

Evidence

There are two types of evidence on the costs of home care for technology-dependent children compared to care in other settings. First, there is evidence on the costs of care for children requiring ventilators and other device-based respiratory supports. Since the evidence is sparse, some information of the costs of care for ventilator-dependent adults is also included here. Second, there is literature regarding the cost of home care for people receiving home intravenous nutrition or drug therapy. In this case, there is little evidence specifically for children, and the programs generally do not send home individuals whose families cannot provide the necessary nursing services. Published comparisons of home care costs with the costs of nonhospital institutional care (e.g., nursing homes) are nonexistent for technology-dependent children in either group.

There is some evidence regarding costs of care for children with less intensive needs, such as those on dialysis or apnea monitors. It is not discussed here because the relative costs of care for these children is less of an issue than the costs of care for children requiring respiratory and nutritional supports.

Evidence on Relative Costs of Care for Ventilator-Dependent Children

The evidence on the relative costs of caring for ventilator-dependent children in alternative settings is incomplete. Cost estimates are typically based on charges or payments and are available for small numbers of children enrolled in a particular program or discharged from a particular institution. All comparisons of home and hospital costs for these children show that their care is almost inevitably less expensive at home. These comparisons demonstrate that there are a considerable number of children for whom home care appears to be less expensive, often dramatically so. However, up to now no payer has reimbursed for an exceptional level of home care unless it is less expensive than hospitalization, so the ventilator-dependent children now on home care are by definition less expensive to care for in this setting.

Table 14 summarizes comparative hospital and home charges for ventilator-dependent people from the literature. Because of the few reports available, adults as well as children have been included. The figures in this table suffer from many of the problems discussed above. The services included in hospital costs are generally much more extensive than those included in home costs, and the fact that the figures are averages disguises high variations in the amount of paid nursing the patients required. Despite these methodological problems, however, table 14 still provides compelling evidence that for some technology-dependent children the home care charges are substantially less that those for intensive or intermediate hospital care.

The primary reason for this difference is simple: when a child is cared for at home, the costs of housing and much of the nursing are borne by the family rather than by the hospital or health care payer. If a child required 24-hour paid nursing at $20 per hour (slightly higher than Medicaid pays in New Mexico), monthly home nursing costs alone would total $14,400—nearly as much as monthly hospital costs in several of the studies in table 14. Thus, the extent to which total home care charges are less than total hospital charges depends largely on the extent to which the family is able and willing to provide nursing care and appropriate facilities for the technology-dependent child. The difference in charges also depends on whether less expensive nursing can be substituted for more expensive care, and on the medical effectiveness of home care. Home care becomes relatively cheaper if it speeds the time until a child achieves minimal dependence (or delays total dependence), and if it minimizes the

Table 14.—Summary of Comparative Average Monthly Charges Presented in the Literature of Ventilator-Dependent Individuals in Hospital and Home Settings

Source	Average hospital charge	Average home charge	Number of patients	Adults (A)/ children (C)	Home costs include some professional shift nursing	Comments
Banaszak, et al., 1981	$15,469	$3,535	2	A	No	—
Burr, et al., 1983	19,613	2,388	6	C	Not given	All hospital charges (not just maintenance charges) are included in hospital figure.
Cabin, 1985	29,113	5,201	1	C	Not given	Hospital charges include charges before patient was medically stable. Home charges include first month home.
Care for Life, 1985	25,063	1,853	—	A,C	Not given	Based on survey of State respiratory therapist representatives' estimation of average charges.
Donn, 1982	19,071	389	12	C	No	Received nasal oxygen only (not ventilation).
Feldman, et al., 1982	17,500	5,704	2	A	Yes (1 patient)	—
Goldberg, 1983	27,435	7,310	2	C	Yes	—
Goldberg, et al., 1984	24,590	7,425	2	C	Yes	—
Kahn, 1984	22,000	5,400	26	C	No (if included, home charges are $8,000)	Hospital charges from intermediate care unit.
Lee, 1983	40,590	5,490	8	C	Not given	Charges are averages during one year, not necessarily before initial discharge home. Two patients were not hospitalized that year.
Perry and Lierman, 1985	51,517	7,361	2	C	Yes (1 patient)	Hospital charges include surgery, acute care. Home "charges" include estimated cost of some services provided at no charge.
Sherman, et al., 1982	40,332	1,943	9	C	Not given	Charges presented here are averages of ranges given in literature report.
Sivak, et al., 1983	15,600	1,760	10	A	Yes (4 patients)	Hospital charges are estimated and include physician charges. Home charges do not include physician charges or initial costs. If startup charges are included, home charges rise to $1,894.
Splaingard, et al., 1983	15,000	775-16,900	47	C	Yes (patient represented by high home charge figure)	Hospital is a rehabilitation hospital. Home care cost does not include drugs.

SOURCES: See references 13, 26, 28, 32, 42, 55, 68, 69, 92, 103, 128, 146, 147, and 149.

frequency of rehospitalization for infections or other problems.

An analysis of more detailed charge and payment data from children who have been served by high-service home care programs is illuminating. Maryland has computed the monthly hospital and home payments for 25 children served by the State's home care program for children requiring respiratory support (93). For these children, the mean third-party payment for the last month of hospitalization (a proxy for typical hospital costs of a child when medically stable) was $24,715 (range: $210 to $41,057). These children were hospitalized an average of 421 days before discharge. The average monthly home care payments for these children, excluding the first month home, was $9,267 (range: $300 to $25,000). First-month payments averaged $9,798, or an average of $531 per child for one-time expenses (93).

In Louisiana, average third-party payments for the last month of hospitalization were comparable to those in Maryland ($25,995 for 19 children), but average monthly home care costs to the Louisiana program were considerably lower (97). Home payments (computed for 21 children) averaged only $3,012 per month, excluding startup costs. Children in this study were all at least partly ventilator dependent. Louisiana Medicaid, the source of support for many of these children, does not pay for home shift nursing, which may explain why the home care payments are so low.

Data from Illinois demonstrate the potential differences between private payers and Medicaid in cost-savings of home care to third-party payers. For children whose care was compensated only by Medicaid, payments for the last month of hospitalization averaged $16,984, while monthly home care payments averaged $6,358 (104). For children who had at least some private coverage, the payment for the last month of hospitalization averaged $26,616, while equivalent home care payments were $6,922. Thus, while the monthly home care payments for children in these two groups are roughly equivalent, the cost savings of home care experienced by private payers (or that would have been experienced had they covered home care) was substantially greater than that experienced by Medicaid alone. (Illinois' Medicaid program pays for a maximum of 45 hospital days per year, which limits program hospital expenditures.)

Evidence on Relative Costs of Home v. Hospital Administration of Intravenous Therapies

Intravenous therapies—prolonged parenteral nutrition and drugs—have followed the pattern of renal dialysis and hemophilia treatment, in which treatments once received exclusively in the hospital have been adapted to the home. (Intravenous drug therapy may also be administered in outpatient settings.) Drug therapy usually takes a few weeks, compared with the months or years common with parenteral nutrition, but in other ways the two therapies have many similarities.

There is little information in the literature regarding relative costs of care in different settings for individuals receiving chemotherapy, but all programs reporting their experiences with home antibiotic therapy have reported substantially lower charges for home treatment compared to hospital inpatient treatment (table 15). In all cases in these programs, patients or their families administered the infusion at home. Patient selection was a vital component of these programs, because inadequately administered infusions can result in ineffective treatment and rehospitalization. In one study, 40 percent of the patients receiving prolonged antibiotic therapy were rejected by the home care program for reasons including inability to administer the antibiotic, poor family support, and poor motivation. Thus, patients who would have required substantial professional nursing to receive home treatment (had it been available)—and thus might have had more expensive home care—could not participate in the program. The major differences in charges for home and hospital treatment in the programs reported in the literature are the need for patient training, planning, and clinic or nurse visits for home patients; and the hospital room charge for hospitalized patients.

Most individuals on parenteral nutrition, too, go home only after they or their families have mastered the techniques and can provide all home care. One case has been reported in which a 58-

Table 15.—Comparative Charges for Home v. Hospital Administration of Intravenous Antibiotics as Reported in the Literature

Study	Home charges	Hospital charges	Comments
Antoniskis, et al., 1978	$69 per day	$243 per day	Separate home and hospital groups studied.
Eron, 1984	$10 per day in charges incurred only by home patients (training clinic visits)	$170 per day in charges incurred only by hospital patients (room charge in community hospital)	Other charges (for services provided to both home and hospital patients) are assumed equal.
Harris, et al., 1986	$207 per day	$428 per day	Charges are for patients treated initially in the hospital, then at home. Hospital charges may include surgery.
Rehm and Weinstein, 1983	$1,652 per illness	$7,380 per illness	Hospital charges are estimates (patients all got home care). Charges are averages over 4 years of the program.
Stiver, et al., 1978	$40 per day	$137 per day	Hospital charges are estimates (patients all got home care).

NOTE: All home infusions in these studies were administered by patients or their families.

SOURCES: See references 6, 50, 78, 132, and 151.

year-old patient was discharged home on parenteral nutrition under the supervision of full-time home nurses (105). When this patient first went home, requiring 12 hours per day of parenteral nutrition administered by a nurse, her home care charges were comparable to charges for hospital care. Her need for parenteral nutrition and the associated nursing care diminished over time, however, lowering the home care charges (105).

The previously-mentioned 1982 survey of home nutrition programs found home care charges for parenteral nutrition that were roughly $3,400 per month for hospital-supplied patients and $4,900 per month for nonhospital-supplied patients (122). Individual programs have reported program costs of serving patients of approximately $1,800 per month (in 1976-78) and approximately $2,700 per month (in 1982-83) for the first year, when costs are highest (48,181). Even after adjusting for inflation, these costs are probably substantially less than the costs of a patient receiving parenteral nutrition in an acute-care hospital. A third study has reported per-patient monthly home care charges of $1,445, compared with hospital charges that would have been approximately $6,170 (23).

Thus, for both intravenous drugs and nutrition, the literature suggests that home treatment provided under an organized program is substantially less expensive to the payer than care in an acute-care hospital, provided that patients are carefully selected and can perform all necessary procedures themselves or with the help of family members. The literature also suggests, however, that home care charges for adult patients who require substantial professional nursing may approach hospital care charges. None of this literature specifically addresses the relative costs of offering these therapies to children in different settings.

CONCLUSIONS

There is no concrete evidence regarding the relative effectiveness of home and hospital care. Home care is generally considered more effective in promoting the psychological and emotional health of children; hospital care is generally considered more effective at providing medical and nursing care when necessary to promote physical health. With the adaptation of sophisticated technologies and care systems to the home, however, there is no reason to believe that home settings cannot be equally effective at promoting physical health. The desire of the family to have the child home, however, and the availability and quality of these sophisticated technologies and care systems, are critical determinants of effectiveness.

Cost savings to third-party payers have become an important factor in their willingness to finance intensive home care. Such cost savings are likely to exist for most children whose families are willing to bear some of the costs of home care, particularly nursing costs, by providing those services at no cost to the payer. However, because the technology-dependent child population is so diverse, and the nonmedical characteristics of the children and their families are so important a factor in nonhospital health care costs, there are no medical or clinical criteria that can be used to classify children according to their expected cost saving. Payers can ensure a high probability of overall cost savings only on a case-by-case basis, where each child is evaluated and the likely total costs of care for that child in alternative settings estimated. Still, some general factors that tend to increase or decrease relative costs (and, sometimes, relative effectiveness) can be identified.

1. *Nursing Costs*: Home care becomes more favorable to third-party payers as family nursing can be substituted for professional nursing, as less expensive professional or paraprofessional help can be safely substituted for more expensive help, and as intensive nursing needs decline. Paid 24-hour nursing may make home care as expensive as hospital care.
2. *Expected Duration of Dependence*: The high startup costs associated with home care can be more easily justified if a child is expected to be technology-dependent for a very long time and ongoing home care costs are relatively low.
3. *Family and Other Environmental Factors*: Some children cannot or should not return to a family home. If foster care cannot be found, there are often few options other than acute-level hospital care for such children, although other appropriate options (e.g., rehabilitation hospitals, pediatric skilled nursing facilities, or group homes) may be less expensive when available.
4. *Availability of Services*: Inadequate availability of respite care or caregivers trained in the appropriate skills can make hospital care the only viable option even where home care might be less expensive if those services existed. Or, choices in home services may be so constrained that families and third-party payers may be forced to pay high prices for the services.
5. *Substitution of Care*: Home care will be likely to reduce third-party payments only if it can substitute for institutional care, rather than augmenting the care of children already being cared for at home by their families. In many cases, however, augmented care—particularly respite care and case management—may be effective in increasing the quality of care and of life for these children, and may reduce rehospitalizations.

Chapter 4

Sources of Financing

Chapter 4

Sources of Financing[1]

INTRODUCTION

Technology-dependent children typically incur high annual treatment costs that may go on for a number of years. As chapter 3 has shown, these costs are substantial in any setting. For example, in Maryland's program for children dependent on ventilators and other respiratory supports, the average third-party payment for long-term care in the hospital was approximately $24,700 per month in 1985 (93). Home care for such children was about $9,300 per month. Although the number of children who become technology dependent each year is small, the financial burden on their families can be staggering. In the absence of public or private insurance, other public funding, or private philanthropy and charity care, these costs would exceed or severely strain the resources of all but the wealthiest families.

The extent to which technology-dependent children have access to adequate financing for health care, and particularly for home care, depends on three factors:

1. the degree to which this population is covered by private insurance or public health care programs,
2. whether the insurance or program covers long-term care at home for this population, and
3. whether the home care benefits are sufficient to finance most of the medical needs of these children.

This chapter first discusses the extent of private insurance coverage among technology-dependent children and the adequacy of insurance for those who are covered. It then discusses the extent of public payment for home care services across the spectrum of available sources of public third-party payment. These sources include not only Medicaid, but also diverse programs targeted to specific groups or providing specific services.

PRIVATE HEALTH INSURANCE COVERAGE FOR TECHNOLOGY-DEPENDENT CHILDREN

This section examines the adequacy of private health insurance in covering the costs associated with the care of technology-dependent children in the hospital and at home. The question is framed as follows: what is the likelihood that a technology-dependent child will have private insurance coverage that is adequate to cover the costs of care in the setting that is most appropriate for child and family?[2] The answer to this question depends on two factors: the likelihood that a technology-dependent child will be privately insured at all; and, once insured, the amount and scope of coverage that the child is likely to have.

Extent of Coverage

Private health insurance is available to children through two avenues: employer-based group health policies offering coverage of employees' dependents, and self-purchase by the family. Self-purchased insurance is generally a great deal more expensive to the family than employer-based group insurance and covers only about 6 percent of all privately insured children (41).

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[1] Parts of this chapter are adapted from a background paper prepared under contract for OTA by Harriette Fox and Ruth Yoshpe entitled, "Technology-Dependent Children's Access to Medicaid Home Care Financing," August 1986.

[2] Note that this question differs from the usual approach to defining the adequacy of insurance coverage, where healthy people make judgments about their willingness to pay to cover the risk of given levels of expense. That *a priori* question may have a very different answer from the *ex post facto* question addressed in this section (see reference 52).

Table 16.—Number and Percent of Children Aged 0 to 12 Years Covered Only by Private Health Insurance, by Income Status, United States, 1986

	Income status			
	Less than 100% of poverty	100% to 199% of poverty	More than 200% of poverty	Total
Total number of children (in thousands)	10,861.6	9,997.7	23,658.9	44,518.2
Number with private health insurance (in thousands)	1,520.6	6,198.6	20,346.6	28,065.8
Percent with private health insurance	14%	62%	86%	63%

SOURCE: U.S. Department of Commerce, Bureau of the Census, Current Population Survey, unpublished data, March 1986.

A substantial majority—62 percent—of American children between the ages of 0 and 12 have private health insurance as their sole source of third-party coverage (table 16). The likelihood of having private insurance depends primarily on the marital status of the mother and on income status. Almost 86 percent of children with family incomes above 200 percent of the Federal poverty level have private health insurance, while only 14 percent of poor children do (41).

Of course, lack of private health insurance does not necessarily imply lack of coverage. Many children (16 percent of those under age 13 in 1986) are covered by Medicaid, Medicare, or the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS). A small proportion of children (4 percent in 1986) have a mixture of public and private insurance. Nonetheless, about 19 percent of all American children under 13 years of age—8.5 million young children—had no health insurance of any kind in 1986.[3]

Technology-dependent and other severely disabled children may be less likely to have private health insurance than children without major health problems. The 1982 National Health Interview Survey found that 53.8 percent of noninstitutionalized children with severe limitations of activity had private insurance, compared with 74.3 percent of children without any limitations (58). The reasons for these disparities may include unavailability of individual coverage for severely disabled children, lack of coverage of preexisting conditions under group plans, lack of coverage beyond lifetime maximum limits, differences in the employment status of parents in the two groups, and parental decisions to rely on public sources of support.

Adequacy of Coverage

The fact that a technology-dependent child is covered under a private health insurance policy does not necessarily mean that the insurance provides adequate financial resources. The insured person's exposure to out-of-pocket expenses depends on the following aspects, which vary widely among insurance plans:

- *First Dollar Deductible*: the amount that the insured must pay each year before he or she is eligible for coverage. This amount may vary by type of benefit (e.g., hospital v. medical).
- *Coinsurance Rate*: the percent of the cost of covered services for which the insured is responsible.
- *Catastrophic Stop-Loss on Out-of-Pocket Expenses*: typically an annual upper limit on the beneficiary's out-of-pocket payments for insured services.
- *Overall Plan Maximums*: limits on the total amount the insurer will pay out on the policy, calculated either as annual, per episode, or life-time limits.
- *Limits on Covered Services*: limits on the type or number of insured services, such as maximum hospital days or home care visits covered.

Because expenses for technology-dependent children are typically catastrophic in nature, and because these children often require complex care, the three most important features of private health insurance plans for these children are the overall plan maximums, the catastrophic stop-loss provisions, and the covered services.

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[3] This estimate is based on the Current Population Survey (41), which asks about health insurance coverage for the previous year. It is not clear whether the estimate relates to a point in time or to the entire previous year. The estimate is in line with point-in-time estimates of other surveys (see reference 152).

Overall Plan Maximums and Stop-Loss Provisions.—The most direct information on the exposure of privately insured children to overall plan maximums comes from the 1977 National Medical Care Expenditure Survey. In that year, approximately 50 million children under 18 years of age had private health insurance, and about 41 million (84 percent) had major medical coverage.[4] Of those children with major medical coverage, only 23 percent had overall plan maximum limits above $250,000 (53).

Several more recent surveys of employee group health plans, summarized in table 17, show how plan maximums and stop-loss features are distributed among private sector group plans. These surveys indicate that over three-fourths of plans (and employees) are subject to some kind of overall plan maximum, with more than one-half of all employees under policies with life-time maximum limits of $500,000 or less.[5]

Data on new group health insurance policies written by insurance companies in 1984 show a definite trend toward higher overall maximum limits. Ninety-three percent of the employees covered by a sample of new group policies written by commercial insurance companies had maximum limits of $1 million or more (80). Although the data from all sources taken together suggest substantial improvement in adequacy since 1979, it is probable that over one-half of privately insured families still have insurance that is inadequate for the catastrophic expenses associated with long-term technology-dependent conditions.

The impact of low lifetime maximums can be demonstrated with preliminary data from the Maryland and Illinois programs for children requiring respiratory support. If hospitalized, Maryland children would, on average, exceed a $250,000 maximum in about one year (even if the insurer paid only 80 percent of charges). Yet the average length of hospital stay for these children was 14 months (93). Even at home, these children would exceed this lifetime maximum within about 3 years. Of 63 children in Illinois' home care program, 42 were supported exclusively through Medicaid, 23 because their private insurance had lapsed (104).

The situation is somewhat better with respect to catastrophic stop-loss coverage. In 1984, more than three-fourths of plans and employees had an annual catastrophic limit on out-of-pocket expenses. Catastrophic limits ensure that families will not be wiped out by coinsurance requirements in the early months or years of expenditures for a technology-dependent child, but they do not lessen the exposure of families to lifetime maximum benefit limits.

Limitations on Covered Services.—Of particular interest to technology-dependent children is the availability of home care coverage. Almost one-half of employees in medium and large business establishments were without any home health care benefits in 1984 (175). Although home health benefits have been introduced increasingly in the recent past as a cost-containment measure (e.g., 11 percent of plans in a survey of large firms reported adding home health care benefits between 1980 and 1982 (121)) it appears that many children would not be eligible under their current plans. (Note that although health maintenance organizations are often thought of as providing comprehensive coverage, they too may have limited home health benefits.)

Not only is home health frequently an uncovered service in private insurance policies, but as structured, these benefits typically do not meet the needs of a child requiring continual nursing care. For example, although over 90 percent of Blue Cross/Blue Shield plans covered home health services in 1984, 95 percent of such plans limited the number of professional nursing visits.[6] About one-half of the plans had annual limits on the

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[4] Major medical coverage provides for a wide array of services and usually includes an annual deductible, coinsurance requirements, and maximum benefit limits. By comparison, basic benefit plans usually provide first-dollar coverage, but cover only a very narrow set of services.

[5] The only exception is reported by Fox and Yoshpe, who surveyed a small sample (60 firms) of employers. This sample may be biased because it was drawn from a data source listing firms with net asset values above a threshhold, suggesting that even the smaller firms in the sample are disproportionately wealthy (58).

[6] Blue Cross/Blue Shield covers about 13 percent of employees in medium and large firms (175).

Table 17.—Surveys of Employer-Sponsored Group Health Insurance Plans

Study	Survey year(s)	Sample	Employee groups covered by survey	Percent of plans (p) or employees (e) with maximums	Percent of plans (p) or employees (e) with lifetime maximums of $500,000 or less	Percent of plans (p) or employees (e) with lifetime maximums of less than $1 million	Percent of plans (p) or employees (e) with stop-loss catastrophic coverage
U.S. DOL-BLS	1984	Probability sample of 1,326 business establishments meeting industry-specific minimum size requirements (ranging from 100 to 240 employees)	Full-time employees	1984: 82% (e)[a]	1984: 52-57% (e)	1984: 53-58% (e)	1984: 76% (e)
Wyatt Co.	1978-84	In 1984, 1,115 firms of all sizes (but mostly large) participating in the study	Salaried employees	1984: 87% (p) 1980: 88% (p)	1984: 52% (p) 1980: 60% (p)		1984: 88% (p)
Hewitt Associates	1979-84	250 major employers; 68% in Fortune 100, 32% in Fortune 500	Salaried employees	1984: 82-87% (p) 1979: 89-90% (p)	1984: 56% (p)[b] 1979: 75% (p)		1984: 87% (p) 1979: 59% (p)
Fox & Yosphe	1986	Random sample of 60 firms of all sizes selected from Dunn & Bradstreet's U.S. Business Directory (small firms) and Business Insurance Directory (medicine and large firms)	All employees	1986: 67% (p)	1986: 16.3% (p)	1986: 25.5% (p)	1986: 80% (p)
Battelle/EBRI	1977-78	Probability sample of small nonagricultural business establishments (less than 250 employers)	All employees	1978: 75-83% (e)[c]			

[a] Calculated as percent of employees with major medical coverage who are subject to overall plan maximum. About 90 percent of plan participants in this sample had major medical coverage. The remainder had basic benefits only, which may not be subject to lifetime limits but which are often subject to specific maximum limits on services.

[b] Calculated as the percent of all employees with lifetime maximums less than this amount. An additional 4 percent of employees who were not subject to lifetime maximums in 1984 were subject to annual or "per cause" maximum.

[c] This is an overstatement, because employees subject to more than one maximum are double-counted.

SOURCES: See references 33, 58, 83, 175, 186.

number of visits, with a median limit of 90 visits per year; only 7 plans covered at least 2 visits per week (20). These plans also vary in the specific home health services covered. For example, physical therapy is covered by all plans with home health benefits, but respiratory therapy is not a covered service in 22 percent of plans (20). None of the Blue Cross/Blue Shield plans in the 1984 survey included hourly ("shift") nursing as a regular home health benefit.

Increasingly, States are using their regulatory authority to require health insurers to offer home health benefits. At present, 13 States have laws requiring coverage of home health services under health insurance plans (5). These State laws cover only those policies written by health insurance companies and do not apply to health plans provided by employers on a self-insured basis. The latter are exempt from State regulation by Section 514 of the Employee Retirement and Income Security Act of 1974 (ERISA, Public Law 93-406). The exemption from State regulation has been a powerful spur to self-insurance by employers, and further increases in mandated benefits are likely to increase the proportion of employers who self-insure (7). Thus, to the extent that families are insured through employer self-insurance, State action to mandate home health benefits is not likely to be an effective mechanism to increase coverage of services to technology-dependent children in the home.

Recent initiatives within the insurance industry itself are more promising. Several health insurance companies have initiated individual benefit management programs, in which the contractural limitations on covered services are waived for certain high-cost patients. Under these programs, the insurance company will pay for services in home and other settings that would normally not be covered, provided that by doing so the company will reduce the rate of outflow of total benefit payments. Four examples of such individual management programs are presented in box D. In a recent survey of employer-sponsored health plans, Fox and Yoshpe found that 53 percent of employers had an individual benefits management program (58),[7] although these programs may not all operate to encourage nonhospital care for technology-dependent children.

As promising as they are, individual management programs by insurers do not eliminate the problems caused by low overall plan maximums, for the insurer typically will not pay beyond those contractual limits. Individual case management *can* extend the length of time before the maximums are reached. However, insurers may have little incentive to offer this important service if they think they will still end up paying out the maximum amount.

A handful of private insurance plans have considered increasing coverage of specific complex home services to beneficiaries as a group. For example, three of the plans responding to the Blue Cross/Blue Shield 1984 survey reported that they were developing or implementing pilot programs specifically for chronically ill children, including ventilator-dependent children. Another three plans were implementing programs for expanding high-technology services in the home, such as intravenous nutrition and drug therapy, but these programs were not specifically targeted at children (20).

MEDICAID

Background Issues

Medicaid[8] provides health insurance to very poor people who are also aged, blind, disabled,

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[7] For reasons discussed in footnote 5 above, the percentage of plans may be overstated.

[8] The Medicaid program is in reality 54 separate State- and territorial-administered programs that are jointly funded by the Federal and State governments. As a condition of Federal funding, the Federal Government requires that the States provide certain services to designated eligible populations; it also limits the services that will be supported by the Federal Government. States, on their part, retain considerable latitude in tailoring their programs to fit their needs.

Arizona is the only State without a formal Medicaid program. It does have a Medicaid demonstration program, but this program does not include all of the services that are mandated by the Federal Government to be covered in other States.

Box D.—Individual Benefits Management Among Private Insurers

A few private insurance companies have chosen to provide augmented home care benefits to technology-dependent children when it can be shown that by doing so the insurer is likely to save money, or at least to extend the length of time the child will be covered before reaching a lifetime maximum. Following are brief descriptions of four examples.

Blue Cross/Blue Shield Federal Employees Benefits Program

The Blue Cross/Blue Shield Association negotiates, on behalf of the 90 independent plans, a benefits package contract with the U.S. Office of Personnel Management. This contract is one of many health insurance options that a Federal employee may choose. All Blue Cross and Blue Shield plans agree to provide this benefit package to enrolled Federal employees in their local jurisdictions. The present contract provides employees with the option of enrolling in a "high" plan, with benefits including 90 home health days of medically necessary service and no hospital benefit limit; or a "low" plan, with a lower premium, higher deductibles and coinsurance, a $2 million limit on covered benefits, and no home health benefits.

Under a pilot project, begun when the first case was brought to the attention of the program in 1983, the Blue Cross/Blue Shield Federal Employee Program can provide home benefits in excess of the contracted benefits to technology-dependent individuals, including children, who: 1) would be eligible for coverage if in the hospital, and 2) will be less expensive to care for at home (155). A number of individuals who have been extended special benefits under this pilot project have been children, primarily infants with respiratory disorders, heart disease, tube feeding or parenteral nutrition requirements, and multiple handicaps.

Aetna

Aetna Life & Casualty is a national for-profit insurance company with regional offices that administer its plans. The company offers augmented home benefits to any policyholder who would be eligible for coverage if in the hospital and will be less expensive to care for at home. Aetna has provided this service since 1983 to all age groups. The company estimates that the program saved $3.5 million in the first year of implementation, $12 million in the second year, and $26 million in the third (38).

Aetna had served 26 children under age 16 in the program as of March 1986. Savings for each case under the program are calculated at least every 6 months, and all cases over $6,000 in cost or with care lasting longer than 6 months are monitored and reviewed by the company's medical director. Benefits can range from an apnea monitor to extensive equipment purchase, home modifications, nursing, and therapy. Benefits cease when the patient is completely rehabilitated or the lifetime benefit level is reached. In the latter case, the patient may keep purchased equipment (38).

The Equitable

The Equitable Life Assurance Society of the United States, a for-profit insurance company, offers a Medical Case Management program as an optional amendment to group health insurance policies. The policy amendment itself carries no extra charge, but in agreeing to the amendment the group policyholder (the employer) agrees to pay the costs of a case coordinator for any relevant cases that arise. As of January 1, 1986, 255 group policyholders had a medical case management agreement with The Equitable, covering approximately 910,000 employees about 2,500,000 total persons (employees plus eligible dependents) (136).

Patients may be referred to the case management program by the company's pre-admission review service, the source of eligibility verification, the employer, the employee or dependent, claims personnel, or providers. The company uses a diagnosis-based trigger for identification of appropriate cases to ensure early referral and the opportunity to establish a rapport with the patient, family, and provider. Included in the diagnostic profile are a number of diagnoses associated with neonatal problems (e.g., congenital heart anomalies or respiratory distress syndrome) and trauma. More diagnostic categories can be added to accommodate the client's need (136).

Under the case management program, case coordinators at The Equitable screen potential cases, assess the medical and other needs of accepted patients, prepare care plans, coordinate the necessary care, and monitor progress. Patients in the program can receive services that would not be reimbursed under the usual insurance contract, such as home modification, family counseling, and transfer to a special rehabilitation hospital (136).

John Hancock

John Hancock Mutual Life Insurance Co., which has a health insurance component, operates a medical case management program that is very similar to The Equitable's. It concentrates on serving trauma patients, high risk infants, and (in the case of older patients) stroke. The program brings a case consultant to certain of these cases to coordinate care and provide benefits not normally available to beneficiaries, such as specialized rehabilitation services and home services, in order to reduce costs while providing appropriate care (56).

members of families with dependent children, or first-time pregnant women ("categorically eligible"). In 35 States and the District of Columbia, people in these categories can also qualify for Medicaid if their medical expenses are sufficiently high that they become poor as a consequence ("medically needy"). Each State has an approved Medicaid plan that details eligibility, coverage, and reimbursement features in that State.

Two features of the Medicaid program are particularly important in the context of care for technology-dependent children. First, eligibility is a vital issue because the Medicaid program is often the third-party payer of last resort for a technology-dependent child. Second, the coverage of complex health services under the State's usual Medicaid rules, and the way these services are paid, affect the setting and amount of care the child receives. Over the past 5 years, concerns about these two features of the program have led to changes in the Federal statute and regulations regarding coverage and reimbursement under special Medicaid rules. Many States have taken advantage of these changes, described later in this section, to enhance coverage for community services provided to technology-dependent children.

Eligibility

All persons receiving payments under the Aid to Families with Dependent Children program (AFDC) are automatically eligible for Medicaid. (Note that in some States, two-parent families cannot qualify for AFDC even if they are very poor.) In addition, Medicaid eligibility in most States is extended to all aged, blind, and disabled individuals (including children) who receive cash assistance under the Federal Supplemental Security Income (SSI) program.[9] Medically needy persons—those who would qualify for these programs but for their incomes, and who have very high medical expenses—can also be made eligible if the State opts to include them.

To be eligible for SSI, an individual must have a disability that is expected to last at least a year (or until death) and must have available income and resources no higher than established limits. By statute, the income and resources of certain relatives, specifically a parent or spouse if he or she is living in the same household as the individual, must be deemed available to the individual. After one month in an institution, however, the individual is considered to be not living in the family household and the relative's income and resources are irrelevant to the eligibility determination (20 U.S.C. 416). In some circumstances, the application of these rules may encourage the institutionalization of individuals who could be cared for at home if Medicaid financing were available.

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[9] In providing Medicaid coverage to SSI beneficiaries, States may select one of two options. They can make all SSI recipients eligible and, if they choose, also provide Medicaid to individuals receiving only optional State payments; or they can limit Medicaid eligibility to individuals who meet requirements more restrictive than those under SSI. The State may be more restrictive in setting financial requirements for income or resources, more restrictive in defining blindness or deafness, or both. Each requirement, however, may not be more restrictive than that in effect under the State's Medicaid plan on Jan. 1, 1972. As of 1983, 14 States required SSI recipients to meet eligibility standards more restrictive than the Federal standard (168).

The linkage of Medicaid eligibility to SSI payments, and SSI payments to institutionalization, allows a child with a long-term disability and inadequate private insurance to receive hospital services under Medicaid, regardless of the income of the child's family. A number of technology-dependent children who would not otherwise be eligible for Medicaid can thus receive hospital services under this rule without their families having to become impoverished. However, until very recently these children were almost invariably ineligible to receive Medicaid reimbursement for equivalent medical care at home, because once home, their families' resources would be deemed to be available to them. This situation received national attention in 1981, after the family of a hospitalized ventilator-dependent child appealed her case to Congress and the President. Limited options for the States to avoid the link between hospitalization and Medicaid benefits now exist and are described later in this section.

Basic coverage and reimbursement

States may pay for hospital care in a number of alternative ways, and they may place restrictions on the amount of hospital care they will pay for (see table 18). States pay hospitals according to a variety of methods, including:

- the costs incurred in serving Medicaid patients;
- prospectively set rates per day, or per admission;
- prospectively set rates arrived at through competitive hospital bidding or through predicted Medicaid caseloads as a proportion of hospital budget; or
- prepaid health plans, in which a health care provider is paid a set amount per enrolled Medicaid individual, regardless of the actual medical care use of that individual.

Under the prepaid or prospectively set rate systems, hospitals have an incentive to reduce the length of hospital stays as much as possible, be-

Table 18.—Medicaid Hospital Inpatient Stay Maximums and Units of Payment in the 50 States[a] and the District of Columbia, 1985

State	Inpatient hospital stay maximum[b]	Inpatient unit of payment
Alabama	12 days/year	per diem
Alaska		percentage of charges
Arizona		competitive bidding
Arkansas	35 days/year	per diem
California		per diem
Colorado		per case
Connecticut		per case
Delaware		cost-based
District of Columbia		per case
Florida	45 days/year	per case
Georgia		per case
Hawaii		per case
Idaho	40 days/year	per case
Illinois	45 days/year	per diem
Indiana		cost-based
Iowa		per diem
Kansas		per diem
Kentucky	14 days/spell of illness	per diem
Louisiana	15 days/year	per case
Maine		global charges
Maryland	separate maximums for each case type	per case
Massachusetts		percentage of charges
Michigan	18 days/year	per case (DRGs)
Minnesota		per case (DRGs)
Mississippi	15 days/year	per diem
Missouri		per diem
Montana		cost-based
Nebraska		per diem
Nevada		per case/per diem
New Hampshire		cost-based
New Jersey		per case (DRGs)
New Mexico		cost-based
New York		per diem
North Carolina	maximums per diem	per diem
North Dakota		cost-based
Ohio	30 days/spell of illness	per case (DRGs)
Oklahoma	10 days/spell of illness	per diem
Oregon	18 days/year	per case (DRGs)
Pennsylvania		per case (DRGs)
Rhode Island		global charges
South Carolina	12 days/year	cost-based
South Dakota		per case (DRGs)
Tennessee	20 days/year	per diem
Texas	30 days/spell of illness	cost-based
Utah		per case (DRGs)
Vermont		per diem
Virginia	21 days/spell of illness	per diem
Washington		per case (DRGs)
West Virginia	20 days/year	cost-based
Wisconsin		per case
Wyoming		cost-based

[a] Arizona's program is a Statewide Medicaid demonstration program.

[b] Some States with limited covered hospital days allow longer stays for EPSDT eligibles.

[c] Early and Periodic Screening, Diagnosis and Treatment program.

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, *Health Care Financing Program Statistics: Analysis of State Medicaid Program Characteristics, 1984* (Baltimore, MD: DHHS, August, 1985); and S.S. Laudecina, *A Comparative Survey of Medicaid Hospital Reimbursement Systems for Inpatient Services, State by State, 1980-1985* (Washington, DC: George Washington University, 1986).

cause they do not recoup any extra payment for longer stays or extra services. Furthermore, even in some States with cost-based reimbursement, hospitals are paid by Medicaid for care only up to a limited number of days. The net effect of these payment methods and limits is to provide hospitals with an incentive to discharge patients as soon as possible, or as soon as the day limit has been reached. If a child cannot be cared for outside the hospital, the hospital is faced with providing indefinite charity care. Medicaid payment thus may cover only a small fraction of the total hospital costs of caring for a technology-dependent child.

States are not required to cover either pediatric nursing home stays or pediatric home care in their Medicaid programs. If they do cover the former, however, they must also cover the latter; and, covering home care means that certain minimum services must be provided.[10] States covering pediatric home care as a normal part of their Medicaid programs (all but three do) must provide some basic services, such as home nursing visits, medical equipment, and supplies (167). States may also cover numerous optional services. As is evident from table 19, the result is considerable variation in the services covered (and the limits to coverage) across States.

Very few States cover the full range of services and technologies needed by a technology-dependent child in a nonhospital setting as a part of their regular Medicaid benefits. For example, 30 States provided no home shift nursing (i.e., private duty nursing) at all in 1984 (167). Furthermore, Medicaid home services vary dramatically in amount even where they are provided. All States covering home services under Medicaid must offer intermittent or part-time home nursing, for instance, but the number of covered nursing visits varies from 50 to 300 visits per year (167).

Special Options for Financing the Home Care of Technology-Dependent Children Under Medicaid

Four special options have been available under the Medicaid program for States to use in extending eligibility and expanding the range of covered services for technology-dependent children who can be cared for in their homes. Three of these options require the States to obtain a federally approved waiver of usual Medicaid rules in order to provide additional services, while the fourth allows changes in eligibility rules but not services. The options are:

1. the individual "Katie Beckett" waiver (phased out after 1984),
2. the Section 2176 regular home- and community-based waiver,
3. the Section 2176 model home- and community-based waiver, and
4. an amendment to a State's Medicaid plan.

A summary of the various provisions of each of these options is presented in table 20.

Individual Waivers

An individual waiver program, created in 1982 by the Secretary of the Department of Health and Human Services (DHHS), was the first Medicaid option designed to address the problems of individuals who remained institutionalized because returning home for less costly medical treatment would result in the loss of SSI and Medicaid eligibility. Commonly referred to as "Katie Beckett" waivers (after the first child to receive one), they were intended as a temporary strategy to permit specified individuals to have Medicaid coverage at home while States pursued the longer range options of 2176 waivers or State plan amendments (47 FR 24274).

Requests for these waivers were accepted from State Medicaid agencies between June 1982 and December 1984. A DHHS interdepartmental review board determined whether or not the usual SSI deeming rules should be applied in each particular case.[11] For each nominated child, the board

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[10] As of 1986, States may, at their option, provide case management and home respiratory care services under Medicaid (Public Law 99-453).

[11] Due to the large number of applications that were not resolved, the board continued to act into 1986.

Table 19.—Summary of Medicaid Home Health Services Provided in 50 States and the District of Columbia, 1984

	Service							
State	Private duty nursing	Part-time nursing	Therapies[a]	Home health aide	Personal care services	Medical supplies/ equipment	Prosthetic devices	Transportation
Alabama	N	A,L	N	A,L	N	L	A,L	L
Alaska	N	A	A	A	N	A	A	A,L
Arkansas	N	U	L	U	L	U	A,L	A
California	N	A,L	A	A,L	N	A	A,L	A
Colorado	N	A	A	A	A,L	A	L	A,L
Connecticut	L	L	U	L	N	U	L	U
Delaware	A,L	U	U	U	N	U	L	A
District of Columbia	U	U	L	U	U	A,L	A,L	N
Florida	N	U	N	U	N	L	L	A,L
Georgia	N	L	A,L	L	N	A	L	L
Hawaii	N	U	U	U	N	A	A,L	A
Idaho	N	L	L	L	L	A,L	N	A
Illinois	A	A	A	A	N	A	L	A
Indiana	L	A	A,L	L	N	A	A	A
Iowa	N	U	L	U	N	L	L	L
Kansas	A,L	L	L	L	A,L	A,L	A	A,L
Kentucky	N	L	L	L	N	A	A,L	A,L
Louisiana	N	L	L	L	N	A,L	A	A,L
Maine	N	U	U	U	N	U	U	L
Maryland	N	L	L	L	A,L	L	L	A,L
Massachusetts	A,L	L	L	L	L	L	L	A
Michigan	N	U	L	U	U	L	A,L	L
Minnesota	L	U	L	U	L	A,L	A,L	A
Mississippi	N	L	L	L	N	L	N	L
Missouri	N	L	L	L	L	L	A,L	L
Montana	L	L	L	L	L	A	A,L	A,L
Nebraska	A	U	U	L	L	A,L	A	U
Nevada	A	A	A	A	A	A	A	A
New Hampshire	A,L	L	L	L	L	A	A	L
New Jersey	N	A	A	A	N	A	A,L	A
New Mexico	N	A,L	A,L	A,L	N	A	A	A
New York	A	A	A	A	A	A	A,L	A
North Carolina	N	L	L	L	N	L	N	L
North Dakota	U	U	U	U	N	U	U	U
Ohio	L	U	A,L	U	N	L	A	A,L
Oklahoma	N	L	N	L	A	L	L	L
Oregon	A	A	A	A	A	A	A	A
Pennsylvania	N	L	L	L	N	A	A,L	A,L
Rhode Island	N	A,L	A,L	A,L	N	A	A	A,L
South Carolina	N	L	L	L	N	A,L	A	A,L
South Dakota	N	A	A,L	A	L	L	L	L
Tennessee	N	L	L	L	N	L	A	L
Texas	N	A,L	N	A,L	A,L	A,L	A,L	L
Utah	A	U	A,L	U	N	A	A,L	A
Vermont	N	L	L	L	N	L	L	L
Virginia	N	U	U	U	N	A,L	N	A
Washington	A,L	L	A,L	L	N	A	A,L	A
West Virginia	A	U	U	U	N	A	A	A
Wisconsin	A	U	A,L	U	A,L	L	A	A,L
Wyoming	N	L	L	U	N	L	L	L
Total: #N	30	0	4	0	30	0	4	1
#U	2	16	8	16	2	5	2	3
#A	13	14	17	13	9	29	31	31
#L	10	30	39	32	14	27	29	28

KEY: N = not provided; U = no limits; A = prior authorization required; L = other limits

[a] Physical, occupational, and speech and hearing. Respiratory therapy has recently been added as an optional Medicaid home health service, but it was not allowable in 1984.

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, *Health Care Financing Program Statistics: Analysis of State Medicaid Program Characteristics, 1984* (Baltimore, MD: U.S. DHHS, August 1985).

Table 20.—Comparison of State Medicaid Options for Extended Home- and Community-Based Care

Option	Categorical eligibility	Income eligibility	Number of individuals able to participate	Geographic areas	Allowable services	Time period
Individual waivers (no longer newly awarded)	Disabled individuals who, because of relatives income, would otherwise be eligible for Medicaid only if institutionalized	Deeming rules are waived	One person per waiver	Not applicable	Regular State Medicaid services only	Individuals eligible until waiver no longer needed
Regular 2176 waiver	State may target to aged or disabled, mentally retarded or developmentally disabled, or mentally ill. Individuals must require level of care provided in ICF, ICF/MR, SNF, or hospital	States may waive deeming rules; may increase income eligibility to 300% of SSI standard	All persons meeting eligibility criteria	May be less than statewide	Can offer certain services otherwise not authorized under Medicaid law; can provide more extensive coverage of regular services	3-year waiver; 5-year renewal
Model 2176 waivers	States can define specific categories of disabled individuals. Individuals must require level of care provided in ICF, ICF/MR, SNF, or hospital	States must waive deeming rules	50 or fewer slots per waiver program	May be less than statewide	Similar to regular 2176 waivers; must offer at least one service in addition to those provided by regular Medicaid	3-year waiver; 5-year renewal
State plan amendment	Disabled individuals under age 19 who, because of relatives' income, would otherwise be eligible for Medicaid only if institutionalized; individual must require level of care provided in a hospital, ICF, ICF/MR, or SNF	Deeming rules are waived	All persons meeting eligibility criteria	statewide	Regular State Medicaid services only	State option

SOURCE: H.B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U.S. Congress, August 1986.

determined whether it would be inequitable under the circumstances to consider family income and resources in assessing the child's eligibility for SSI payments (and thus Medicaid). For the board to waive the deeming requirements, it had to decide that:

1. enabling the individual to be eligible for home-based care would result in reduced Medicaid expenditures, and
2. the quality of the home-based care would be as good as or better than that provided in an institution.

The board also could impose additional standards in particular cases, depending on the facts presented.

Once a waiver was approved, it remained in effect—and the individual retained Medicaid eligibility at home—until the waiver was no longer appropriate. This would be the case if the individual could no longer meet the SSI disability criteria; if the countable income and resources of the parent (or spouse) fell below the SSI or State supplement standard; or if a waivered child reached the age of 19, at which time he or she could qualify for SSI and Medicaid as an adult without consideration of parental income and resources.

The obvious attraction of the individual waiver option for States was the ability to provide more appropriate Medicaid coverage for selected individuals. States pursued the option as a short-term response to a small number of extraordinary cases, usually in the face of significant public pressure. But since the waiver only entitled individuals to regular Medicaid services, States without many Medicaid home care benefits may have found it difficult to use this option unless other sources of home care financing were available to the child as well.

States used this option not only to cover institutionalized children who needed the deeming rules waived in order to return home, but also to cover disabled children already at home. In some instances, these children needed Medicaid benefits as a backup for private insurance; in others, they already were SSI- and Medicaid-eligible and needed the deeming rules waived so that their parents would be permitted to earn higher incomes.

Regular 2176 Waivers

These waivers, authorized by Congress in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35), enable States to finance a wide array of home- and community-based services for Medicaid recipients who otherwise would require institutionalization. Under the waivers, States can designate specific target populations who will be subject to broader income eligibility policies and receive a wider range of home- and community-based services than normally covered under the State plan.

Eligibility for regular 2176 waiver programs is limited to Medicaid recipients who, in the absence of home and community services, would require long-term care in a skilled nursing facility (SNF), intermediate care facility (ICF), or hospital. Special reference to hospital-level care for the ventilator population (Public Law 99-272) and for all other individuals (Public Law 99-509) was added to the statute in 1986. Even before the addition, States could have included hospitalized individuals in these waiver programs, but this policy was unwritten and not clearly communicated to the States (59).

States must specify a projected number of people to be served under the waiver. In defining the population to be served, States must select a target group from one of the following three categories or subcategories of Medicaid recipients: aged or disabled, or both; mentally retarded or developmentally disabled, or both; or the mentally ill. (States can have more than one waiver if they wish to serve more than one group.) In addition, they may restrict eligibility for participation in the waiver to:

- individuals residing within a certain geographic area of the State,
- individuals being discharged from a long-term care institution, or
- those particular individuals for whom the Medicaid cost of providing home- and community-based services is less than the cost of providing institutional care.

A State can also expand income eligibility for the target waiver population beyond that of the regular Medicaid program in two ways. One is to increase Medicaid income eligibility limits to a level equal to three times the maximum payment made to an individual under the SSI program. (Individuals becoming eligible under this higher income standard, however, would be required to contribute to the cost of their care.) The other option is not to deem a certain portion of the family's income to be available to an individual who receives care at home. Once a State has set its eligibility criteria for a 2176 waiver program, *all individuals who apply to the program and meet the specified criteria must be accepted until the projected limit is reached.*

States may provide services under the waiver that are otherwise not allowed by Medicaid, such as respite care and habilitation services.[12] They can also expand the amount, duration, or scope of coverage of regular Medicaid services offered in that State. Among the various regular Medicaid services that have been offered more extensively under the waiver are case management, hourly nursing care, home health aides, personal care services, medical supplies, and durable medical equipment. States may also offer other services approved by the Secretary, such as minor home modifications and utility expenses.

To receive waiver approval, it is essential for a State to show that its proposed program of augmented services will be no more costly to the Medicaid program than institutional care. Estimated per capita expenditures for all Medicaid services provided to all long-term care recipients, including both home and hospitalization, cannot be greater than they would have been in the absence of the waiver (42 CFR 441). States that want to serve technology-dependent children are able to compare the cost of their home care to the cost of hospitalization using the prescribed formula. Given that the waiver naturally increases the number of Medicaid recipients receiving long-term care services in the home, a waiver application usually is expected to demonstrate cost savings in two ways: by showing that the total cost of home- and community-based services is less than the total cost of institutional care, and by documenting that the waiver will afford a reduction in the number of Medicaid beneficiaries receiving institutional care.

The advantage of the regular 2176 waiver is its flexibility. Eligible groups can be defined narrowly or broadly, and the waiver can be applied to the entire State or only to a small area. States can, if they wish, use a regular 2176 waiver to serve a relatively small group of disabled children who otherwise would be hospitalized. The often prolonged process of completing the very detailed waiver application, however, may have discouraged States from targeting these waivers to this small population. Regular 2176 waivers generally are perceived by the States as being for larger and more inclusive populations, such as the elderly and disabled, and incorporating technology-dependent children into such a waiver is not attractive to all States. For one thing, States appear reluctant to waive the SSI deeming rules for the large number of recipients who would be eligible under the waiver. For another, they seem to prefer to control the number of very high-cost individuals who come into the program for fear of exceeding their original cost estimates and having their renewal request denied.[13]

Model 2176 Waivers for the Disabled

Using its statutory authority for regular 2176 waivers, the Health Care Financing Administration (HCFA) developed a "model" 2176 waiver in December 1982 to encourage States to provide home- and community-based services to certain disabled individuals who otherwise would lose Medicaid eligibility outside of an institution.[14] A model waiver is similar to a regular waiver except in two essential respects:

1. it may serve no more than 50 blind or disabled children and adults at any one time,[15] and

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[12] Habilitation services now include prevocational, educational, and supported employment services for discharged nursing home patients (effective Apr. 6, 1986) (Public Law 99-272).

[13] Although the States perceive this as a real obstacle, HCFA staff report that they routinely grant approval for higher cost ceilings where States have incurred unanticipated expenses for medically necessary services. (Between March 1985 and April 1986, before Public Law 99-272 prohibited this practice, the Health Care Financing Administration had been denying Federal matching payments for Medicaid expenditures that exceeded a State's original cost ceilings.)

[14] See the State Medicaid Manual, Part 3—Eligibility, transmittal no. 1, February 1983 and final regulations at 42 CFR 441.300.

[15] Prior to the enactment of Public Law 99-272 in 1985, States operating under a model waiver were able to serve only 50 unduplicated recipients, which meant that participants who died or left the program for any reason could not be replaced.

2. it *must* provide that the SSI income deeming rules are waived to permit Medicaid eligibility for noninstitutional services.

HCFA's intention was to assist States in moving quickly through the waiver application process and to eliminate the need for individual waivers (47 FR 24274). States applying for the model waiver must meet all of the basic statutory and regulatory requirements for regular 2176 waivers but are required to offer only one home- or community-based waivered service. As under the regular 2176 waiver, States may target their programs to particular subgroups of the disabled population.

Once a model waiver is approved, States can admit only those eligible individuals whose estimated home care costs are below the estimated costs for institutionalization. By contrast, under a regular waiver, States need only show that Medicaid's *average* per capita costs with the waiver would be less than they would be without the waiver.

The advantage of the model waiver is that it gives States a built-in cap on costs and a chance to gain experience with home care for the disabled on a small scale. In addition, States interested in serving children who otherwise would be hospitalized generally find that a model waiver request is more likely to be approved by HCFA than a regular waiver request. The standardized application form makes it possible to isolate a small, closely defined group of these children and show, on a case-by-case basis, the often dramatic program cost savings of caring for them at home. If the model waiver is targeted exclusively to technology-dependent children, the State also can avoid the requirement of the regular waiver to document a reduction in the number of nursing home residents. The 50-person limit, however, may mean that some States must apply for more than one waiver to serve this population adequately.

State Plan Amendment

In addition to the waiver options, States have the option of amending their State plans to expand Medicaid eligibility to disabled children under age 19 living at home who, because of the SSI deeming rules, otherwise would be eligible for Medicaid only if institutionalized (Public Law 97-248). Only the normal range of covered Medicaid services in that State are available under this option; special services cannot be added solely for this particular group. States must ascertain for each child that home care is appropriate, and that the cost of this care is less than it would be in an institution of the appropriate care level. Once a State amends its plan, all children meeting the eligibility criteria, whether or not institutionalized, must be allowed to participate. A State can elect to discontinue coverage for this group of children at any time.

The State plan option does not require a State to prepare cost documentation or to await a lengthy approval process. States are free to develop their own implementing regulations. Yet, some States have viewed the option as being too broad and having the potential of extending Medicaid eligibility to large numbers of children who are currently being cared for in the community. From the perspective of families and providers, however, the option's major drawback is that in States with meager Medicaid home care benefits a technology-dependent child's requirements for services may not be adequately met.

State Use of Medicaid Options to Serve Technology-Dependent Children

An overview of State experience with the four Medicaid options is presented in table 21. This table summarizes waivers serving physically disabled, but not mentally or developmentally disabled, children. Although at least one State (New Mexico) uses a waiver for the developmentally disabled population as its major vehicle for providing extended Medicaid home care services to technology-dependent children, and other States may serve a few such children under such waivers, most States thus far include technology-dependent children under waivers for the physically disabled.

Thirty-three States were serving technology-dependent and other physically disabled children through a waiver as of April 1986.[16] Eight States were providing these children with special home

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[16] A number of States were renewing waivers in 1986, so these numbers may have changed.

Table 21.—State Activity in Medicaid Home- and Community-Based Service Options as of Apr. 15, 1986

State	Regular waivers serving disabled children: Approved waivers	Regular waivers serving disabled children: Number of children served	Model waivers serving disabled children: Approved waivers	Model waivers serving disabled children: Number of children served	State plan amendment: Approved plan change	State plan amendment: Number of children served	Individual waivers for children (number of waivers)
Alabama	1	9					
Alaska							
Arizona							
Arkansas					Yes	47	
California	1	60					
Colorado							Yes (7)
Connecticut			1	6			
Delaware							Yes (8)
District of Columbia							
Florida							
Georgia			3	7	Yes	0	Yes (18)
Hawaii							
Idaho	1	31	1	3	Yes	100	
Illinois			1	50			Yes (30
Indiana							Yes (1)
Iowa			1	14			Yes (10)
Kansas							
Kentucky	1	36					
Louisiana							Yes (2)
Maine					Yes	66	
Maryland			1	13			
Massachusetts					Yes	[a]	Yes (28)
Michigan			2	38			
Minnesota			1	14	Pending[b]		
Mississippi			1	0			
Missouri	1	23					
Montana	1	30					
Nebraska							
Nevada					Yes	5	Yes (2)
New Hampshire							
New Jersey	1	3	3	40			Yes (6)
New Mexico			1	25			Yes (1)
New York			1	3			Yes (6)
North Carolina			1	7			
North Dakota							
Ohio			1	24			
Oklahoma							
Oregon							
Pennsylvania							Yes (13)
Rhode Island					Yes	12	
South Carolina							
South Dakota					Yes	1	
Tennessee							
Texas							
Utah							
Vermont							
Virginia							
Washington	1	15					
West Virginia							Yes (2)
Wisconsin					Yes	100	
Wyoming							
Total "yes" answers	**8**	**207**	**19**	**244**	**9**	**331**	**14 134**

[a] Massachusetts began admitting children under this eligibility provision in fiscal year 1987.

[b] Minnesota's State Plan Amendment has been approved by the State and is pending in HCFA.

SOURCE: H.B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U.S. Congress, August 1986.

care services under a regular 2176 waiver and 14 States were broadening their eligibility as well as their benefits through 19 separate model waivers. In addition, nine States had amended their plans (a tenth has now been added) and 14 had requested and received individual waivers.

Together these options have been serving 938 physically disabled children. Technology-dependent children who require device-based respiratory or nutritional support (equivalent to Groups I through III in this Technical Memorandum) appear to comprise over 60 percent of the under 21 population receiving home care under one of the three waiver programs (47).[17] Among the other physically disabled children covered by the waivers, about 25 percent have central nervous system disorders (e.g., cerebral palsy, quadriplegia, or spina bifida), and about 10 to 15 percent are characterized by congenital, metabolic, or immune disorders (e.g., cystic fibrosis or congenital heart disease,) or by injury-induced trauma.

In the 17 States without either waivers or a State plan amendment, technology-dependent children are subject to the same Medicaid eligibility requirements and home care coverage that other Medicaid recipients are. In these remaining States, children who cannot qualify for Medicaid as categorically eligible or medically needy may rely on Maternal and Child Health program funds for some home services; or they may remain in an institution in order to retain Medicaid eligibility. Children who can qualify for Medicaid as poor or medically needy individuals may receive regular Medicaid home services; or, in one or two States, they may be able to receive certain additional home services under the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.[18]

Practices Limiting Use of the Medicaid Options

The special Medicaid options that can be used to extend services to technology-dependent children are limited by Federal statute and regulations, State implementation, and insufficient knowledge and understanding of the options. While some limits are unintended, others are the result of conscious efforts to control costs, or the result of serving technology-dependent children under waivers that were tailored primarily for the elderly population. For example, the requirement that a State must prove that a 2176 waiver will not increase Medicaid costs is one that for many States entails expensive and difficult documentation. In a second example, the fact that children with eligibility under the State plan amendment option can receive only regular Medicaid home health coverage means that this option may be only minimally useful in some States unless general coverage is expanded. And, expanding coverage would mean extending the home services available to all Medicaid recipients, including the elderly, which many States fear will be very costly.

A number of States have argued that HCFA procedures for waiver approval are unduly confusing and time-consuming. HCFA, on the other hand, argues that the process is relatively straightforward if States are adequately prepared and that HCFA itself offers assistance in preparing the applications. Both of these perspectives are probably valid. A lack of communication and understanding between HCFA and the States seems to have contributed to a reluctance on the part of some States to apply for waivers (or to implement State plan amendments), to follow through on the applications, or to tailor the waivers to the needs of technology-dependent children.

Although a substantial number of 2176 waivers and State plan amendments are in effect, in many States not as many technology-dependent children as might be expected are receiving the benefits of these options. Variation in the use of waivers is frequently a function of the way a program is structured with regard to income eligibility, categorical eligibility, cost-saving determinations, and service coverage. Specific State restrictions that can limit access of technology-dependent children to Medicaid services include:

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[17] Comparable diagnostic information was not available for children receiving home care services under a State plan amendment.

[18] EPSDT is a separately authorized program under Medicaid offered to all low-income, Medicaid-eligible children. Its function is to detect and treat correctable abnormalities in children, such as vision and dental problems. EPSDT services are not subject to the same Federal limits and requirements as other Medicaid services, and under EPSDT States can offer services to poor children that are not available to other Medicaid beneficiaries.

- not waiving SSI deeming rules (possible only under the regular 2176 waivers, since these rules must be waived under a model waiver),
- restricting eligibility for a waiver only to certain disease categories (possible only under model waivers),
- allowing waivered services only to individuals actually discharged from an institution,
- not allowing home care costs to be compared against the costs of hospitalization (as opposed to SNFs or ICFs),
- limiting reimbursable hospital days (which may make it difficult to show program cost savings from home care to Medicaid),
- not covering skilled shift nursing (i.e., private duty nursing) as a regular or a waivered service, and
- not expanding in other ways the range of regular Medicaid home services available when relying on an individual waiver or State plan amendment to serve the needs of the technology-dependent population.

Tables 22, 23, and 24 summarize the restrictions of the various home care options in specific States.

In some instances, the State's "attitude" toward financing the care of these high-cost children, a more subtle program feature to capture, is the real determinant of how many technology-dependent (and other physically impaired) children receive Medicaid home care benefits. For example, only about one-half of the States operating Section 2176 waiver programs that include children routinely inform the families of children who face long-term hospitalization of their right to be evaluated for waiver program participation (59). Moreover, only one-fourth of the States with regular waivers and 15 percent of those with model waivers report that they publicize the availability of their programs. In Georgia, which sought (and received) three model waivers in response to great political pressure to help a few particular children, not even hospital discharge planners have been told about the waivers. Indeed, even among the Medicaid agency staff, there is much confusion and misinformation about whether additional children may be covered. A similar situation exists in Mississippi.

Many of the waiver and amendment programs have had long initial delays, often due to a shortage of case managers and home health agency personnel. In such instances, disabled children, like other potential participants, have been unable to obtain the intended home care benefits.

For the most part, the 2176 waiver programs—particularly the regular waivers—have been designed and used to serve populations other than physically impaired children. Accordingly, these waiver programs often have State restrictions intended as gatekeeping mechanisms to reduce program costs, but in practice the restrictions act to limit the usefulness of these programs for technology-dependent children.

STATE-PROVIDED SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Prior to 1981, States provided a number of specific health services to women and children under a series of categorical grants, authorized under Title V of the Social Security Act and jointly funded by the States and the Federal Government. These services included maternal and child health services; crippled children's services; supplemental security income services for disabled children; hemophilia treatment centers; and other programs aimed at specific groups or health problems. The 1981 Omnibus Budget Reconciliation Act (Public Law 97-35) replaced these categorical grants with a single block grant to each State, eliminating most of the requirement for specific services and allowing greater State discretion. A specified portion of the total funding continued to be set

Table 22.—State Policies and Practices That Limit Participation Under the Regular Waiver Programs That Theoretically Could Serve Physically Disabled Children, April 1986

		Income eligibility restrictions			Categorical eligibility restrictions		Service limitations							
State (year implemented)	Number and percent of participants under 21	Does not waive SSI income deeming rule	Does not allow income at 300% of SSI level	Does not include medically needy in addition to categorically eligible	Specifies certain disease categories	Requires participants to be in an institution	Does not use hospital cost comparison	Limits hospital day coverage and allows no exceptions	Does not use SNF cost comparison	Does not cover SNFs for individuals under 21	Requires every individual to show lower expected costs under the waiver	Package of waivered services is not designed to serve physically disabled children	Does not cover skilled shift nursing (as a waivered service or under the State plan	Relies heavily on private insurance, voluntary services and/or family-delivered services
Alabama (1984)	9 (0%)	X	X	N/A			X	X			X	X	X	
California (1985)	60 (48%)	X	X								X			
Florida (1985)	0 (0%)	X	X	N/A			X		X	X	X	X		
Georgia (1984)	0 (0%)	X	X	N/A			X	X	X					
Idaho (1984)	31 (12%)	X	X	N/A			X	X			X		X	X
Kentucky (1983)	36 (18%)	X	X	X			X	X					X	X
Missouri (1925)	23 (9C%)	X	X	N/A										
Montana (1983)	3 (6%)											X		
New Jersey (1983)	3 (0%)			N/A			X				X			
Rhode Island (1982) (renewed 1985)	0 (0%)	X	X				X		X		X	X	X	
South Carolina (1984)	0 (0%)	X		X			X	X			X	X	X	
Virginia (1982) (renewed 1985)	0 (0%)						X				X	X	X	
Washington (1982)	15 (2%)			X		X	X							

NA = Not applicable in that State.

SOURCE: H.B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U.S. Congress, August 1986.

Table 23.—State Policies and Practices That Limit Participation Under the Model Waiver Programs, April 1986

		Categorical eligibility restrictions				Service cost limitations		Service limitations		
State (year implemented)	Number and percent of participants under age 21	Specifies certain disease categories	Requires certification for ICF level-of-care	Does not cover SNFs for individuals under 21	Requires participants to be in an institution	Does not use hospital cost comparisons	Limits hospital day coverage and allows no exceptions	Package of waivered services is not designed to serve physically disabled children	Does not cover skilled shift nursing (as a waivered service or under the State Plan)	Relies heavily on private insurance, voluntary services, and/or family delivered services
Connecticut (1982)	7 (86%)					X				X
Georgia I (1983)	3 (100%)	X			X	X				
Georgia II (1984)	2 (100%)	X			X					
Georgia III (1984)	2 (100%)	X			X	X				
Idaho (1983)	30 (10%)					X	X		X	X
Illinois (1984)	50 (100%)									
Iowa (1984)	14 (67%)					X			X	
Maryland (1985)	13 (100%)									
Michigan I (1983)	40 (100%)				X	a				
Michigan II (1985)	3 (100%)	X				X				
Minnesota (1985)	14 (100%)									
Mississippi[b] (1983)	0 (0%)					X	X		X	
New Jersey I[c] (1983)	23 (52%)									
New Jersey II[c] (1985)	14 (39%)									
New Jersey III[c] (1985)	3 (100%)				X					
New Mexico (1984)	25 (100%)		X			X				
New York I (1984)	3 (100%)				X	X				
New York II (1985)	0 (0%)					X		X		
North Carolina (1983)	25 (100%)									
Ohio I (1983)	42 (100%)									
Ohio II (1985)	0 (0%)					X		X		

[a] Michigan compares the cost of home care to 60 percent of the DRG hospital reimbursement.

[b] The Mississippi model waiver has not served any clients and therefore has no program experience.

[c] New Jersey's Medically Needy Program began in July 1986, but the waiver programs do not cover the medically needy.

SOURCE: H.B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U.S. Congress, August 1986.

Table 24.—State Policies and Practices That Limit Participation Under the State Plan Amendment, April 1986

	Service limitations			Service cost limitations			
State (year implemented)	Number of children covered under this provision	State plan does not cover skilled shift nursing	State relies heavily on private insurance, voluntary services, and/or family delivered services	Does not use hospital cost comparison	State plan limits hospital coverage and allows no exemptions	Does not use SNF cost comparison	State plan does not cover SNFs for individuals under age 21
Arkansas (1985)	47	X	X				
Georgia (1982)	0	X		X		X	
Idaho (1984)	100	X	X	X	X		
Maine (1983)	49	X[a]					
Massachusetts (1986)	0[b]						
Nevada (1982)	5						
Rhode Island (1985)	12	X					
South Dakota (1985)	1	X		X			
Wisconsin (1983)	100		X				

[a] Maine is amending its State plan to include skilled nursing.
[b] Massachusetts began admitting children under this eligibility provision in fiscal year 1987.

SOURCE: H.B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U.S. Congress, August 1986.

aside, however, for special demonstration projects, training, and genetic disease and hemophilia programs (158).

Under the present Maternal and Child Health (MCH) block grant program, States must match every 4 Federal dollars with 3 State dollars.[19] An evaluation of the implementation of the block grant program by the General Accounting Office (GAO) found that States tended to spend their allotments in ways substantially similar to prior patterns (158). In all 13 States studied by GAO in 1984, States were offering extensive services to crippled children (recently redesignated "children with special health care needs" (CSHCN)). Services offered by the States were extensive. Most States had actually increased their funding for these services, and four of the 13 States had added new services. The programs themselves showed great diversity, however, maintaining differences that existed before the block grant was established. Most program funds are now spent on screening and treatment of handicapping conditions. However, they also fund a variety of ongoing support services such as counseling and case management. A few States operate State-owned hospitals for handicapped children.

The population served by the CSHCN program has changed considerably since 1935, when the program was first enacted. Originally, Title V specified that the program was to provide diagnostic, corrective, and rehabilitation services to children with crippling conditions, such as polio and cerebral palsy. Over time, however, the original program has expanded in many States to serve children with a wide range of chronic health conditions, and the ventilator-dependent child is a recent example of the new population (107).

The States interviewed by GAO typically provided CSHCN services through State health agencies and physicians on a fee-for-service basis. Services include "screening, diagnosis, surgical and other corrective procedures, hospitalization and after care, and speech, hearing, vision, and psychological care" (158). The Federal legislation establishing the MCH block grant prohibits the charging of fees to low-income mothers and children and requires that when fees are charged they reflect the income, resources, and family size of the beneficiary. A number of States have sliding fee schedules for services (158).

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[19] The Federal Government spent $67 million on handicapped children's services in 1983, most of it from the block grant (amounting to 23 percent of the total MCH grant) (8). States spent an additional $247.6 million, some of which was matching MCH funds.

CSHCN is a strongly clinic-based program in most States, actually providing some or all of the covered services (rather than simply reimbursing for them, as Medicaid does) (36). It is often coordinated with Medicaid; in many clinics, the CSHCN program provides the services and Medicaid reimburses the clinic for services provided to Medicaid-eligible individuals (135).

Despite the traditional emphasis of clinic-based care, most CSHCN programs fund or provide at least a limited amount of home care services, and some provide a fairly wide array of such services. The CSHCN program in Los Angeles County, California, for example, will provide or pay for home nursing services, physical and occupational therapy, respite care, and other home services. The program also provides case management for children receiving home health services, and training for families of technology-dependent children (103).

The CSHCN programs are a particularly significant source of funded care for technology-dependent children in Illinois, Louisiana, and Maryland. Between 1983 and 1986, these three States were recipients of MCH demonstration project funds for Special Projects of Regional and National Significance (SPRANS). They developed programs, extentions of their CSHCN programs, aimed at appropriate long-term care for ventilator-dependent children. The programs had two principal design objectives:

1. to develop a regionalized system of care for such children; and
2. to develop a comprehensive, coordinated model of care.

The SPRANS programs of the three States differ in a number of ways. Illinois and Louisiana originally targeted only ventilator-dependent children under age 22, while Maryland targeted all children requiring some specialized respiratory support under age 18. Louisiana and Illinois run their programs out of single hospital-based centers, while Maryland's program is based in a consortium of several hospitals with a coordinating board. All programs, however, emphasize training of parents and professionals, case management and coordination of care, and care in nonhospital settings.

Through the SPRANS projects, the CSHCN program has focused attention on ventilator-dependent children and their problems in acquiring community care. These projects, and programs in certain other States, have centered on the CSHCN program as a coordinator of care. Observers and program administrators have noted that children's health services have tended to be fragmented and disease-specific, and that State CSHCN programs should seek a role in the coordination, not just the provision, of services required by technology-dependent children (106,177). Some of the State CSHCN agencies appear eager to take on this responsibility.

A COMPARISON OF HOME CARE BENEFITS IN FIVE STATES: THREE HYPOTHETICAL CASES

Because eligibility criteria, covered services, and payment mechanisms for Medicaid and CSHCN services vary so dramatically across the 50 States, it is difficult to describe generally a technology-dependent child's access to publicly financed home health services. A child may have access to excellent services in one jurisdiction but be able to receive little or no financial assistance for noninstitutional care in another. Furthermore, a State that offers little access to Medicaid services to one child may offer substantial services through its CSHCN program, and the reverse might be true in another State. Some States that seem, on paper, to offer few services in reality have innovative ways of extending certain vital services to at least a limited population. On the other hand, States with apparently generous benefits may be very strict in actually authorizing them.

In order to portray the diversity among States, this section examines the opportunities for home care coverage that three hypothetical children could expect in five different States: California, Georgia, Kansas, Maryland, and Missouri. The States were chosen to reflect diversity in size, geography, and urban-rural composition, and also to represent a wide range of Medicaid and CSHCN program designs. The services available to the three hypothetical children in each State are described below.

Case 1: "K"

"K" is a hospitalized 8-month-old infant with severe bronchopulmonary dysplasia. She is medically stable but still requires full-time ventilator and tracheostomy care (suctioning up to 50 times a day) and special formula feeding through a nasogastric tube five times a day. She also receives medication treatments, chest physical therapy, and range of motion exercises four times daily. The monthly cost of her home care is projected to be about $7,620 ($6,650 for paid nursing, $300 for equipment, $600 for supplies, $50 for medication, and $20 for a physician visit). There would be additional initial costs of approximately $900 to cover equipment and supplies. Costs could decline as she is weaned from the ventilator.

"K" 's mother is single and unemployed; she will rely on AFDC and food stamps to support "K" and two other children. "K" 's grandmother also lives with the family.

Medicaid Services

"K," as an AFDC recipient, would be automatically eligible for regular Medicaid home care services in all five States. In Maryland, California, and Missouri, "K" would be eligible to receive augmented home services through a 2176 waiver program. (Maryland has a model waiver program to serve severely disabled children. California and Missouri both operate regular waiver programs that can include disabled children and allow home care costs to be considered against the cost of hospitalization.) In these three States, the waivers are routinely used to serve ventilator-dependent children and could provide all of the home care benefits that "K" requires.

Although Georgia operates a model waiver program specifically for ventilator-dependent children and "K" would meet the established eligibility criteria, it is not clear whether she could participate. Thus far, the State has elected to serve only three ventilator-dependent children, each of whom is comatose. Medicaid staff report that, for financial reasons, the agency is not interested in increasing the number of children receiving intensive home care services under the model waiver.[20]

"K" would be dependent on nonwaivered Medicaid services in Kansas and probably also in Georgia.[21] In Kansas, most of her home care needs could be reimbursed through EPSDT, because the State allows home care benefits up to $240 per day through this special Medicaid program. However, "K" 's home care needs most likely could not be met in Georgia, where she would receive only those Medicaid services regularly available under the State plan—physician services, medication, a limited number of intermittent nursing visits, and the ventilator equipment itself.

CSHCN Support

Extensive case management assistance for "K" 's family could be provided in California, Kansas, Maryland, and Missouri, because the CSHCN program in each of these States has agreed to manage the care of Medicaid children with complex medical needs. In Georgia, though, CSHCN case management expertise would not be available.

Basic differences in home care benefits among CSHCN programs could affect "K" 's potential for hospital discharge. In California and Maryland, two States in which Medicaid benefits available to "K" are already substantial, CSHCN programs would be willing to provide certain gap-filling services that may not be fully financed through Medicaid. Missouri CSHCN also could provide equipment, supplies, and some therapeutic services. Yet in Georgia, neither Medicaid nor the CSHCN program would cover "K" 's skilled nursing care.

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[20] Many children meet the model waiver criteria but have not been brought into the program. At present, in one hospital alone, there are more than 20 ventilator-dependent children unable to obtain home care financing.

[21] Georgia uses a maximum monthly home care service limit of $1,200 in determining an individual child's eligibility. Kansas uses a standard of $240 per day. However, since total parenteral nutrition would be an additional inpatient hospital cost, it is calculated as an additional home care cost above the maximum day rate.

Case 2: "M"

"M" is an 18-month-old toddler who has been hospitalized since birth due to multiple metabolic and developmental problems, including insulin-dependent diabetes, congenital heart disease, seizures, liver dysfunction, and failure to thrive. "M" 's mother, who is divorced and has no other children, is eager to bring him home and would provide much of his care herself. Once home, "M" will continue to require an evaluation and adjustment of his diet on a daily basis, monitoring of his blood glucose level four times each day, and 12 different medications, some of which must be taken two or three times daily. The estimated monthly cost of his home care is $4,320 ($3,700 for nursing, $70 for equipment, $280 for supplies, $250 for medication, and $20 for a physician visit).

"M" 's mother earns $14,500 per year and has saved $2,800. Her employee health benefits were meager and ran out quickly during "M" 's prolonged hospital stay.

Medicaid Services

"M"'s disability and low family income make him eligible to receive SSI cash benefits. In four of the five States—California, Georgia, Kansas, and Maryland—he, therefore, would be eligible for Medicaid (and regular Medicaid home health benefits) as well. Missouri, however, has elected not to provide Medicaid benefits to SSI recipients under age 21 unless they are residents of an ICF. "M," in fact, would have no opportunity to be covered by Medicaid in Missouri. His mother's income places them far above the AFDC payment level and Missouri does not provide benefits to the medically needy.

Under the Maryland and California waiver programs, "M" could be covered by Medicaid for his complete home care package. He would also be covered in Kansas under its EPSDT program, which in that State is used to fund extensive treatment services for certain chronically ill children. In Georgia, the most expensive part of his care—the skilled shift nursing service—could not be reimbursed, although medication, equipment, supplies, and physician visits could. Although Georgia has three model waivers for disabled children, "M" would not be able to participate in any of these.

CSHCN Support

In Maryland and Kansas, two of the three States where "M"'s home care needs could be financed adequately by Medicaid, case management and family training would be provided through an arrangement with the CSHCN program. The Maryland and also the California program could contribute certain services, supplies, and equipment in the event that these were not covered by Medicaid. The California CSHCN program does not charge Medicaid recipients, but the Maryland program would require "M"'s family to pay a small co-payment charge. In Georgia, where the Medicaid home care benefits available to "M" would be minimal, the CSHCN program could provide his family no additional assistance. "M" would be financially eligible for CSHCN services at no charge, but the agency neither finances nor arranges for skilled shift nursing care at home.

In Missouri, where "M" would not have access to Medicaid benefits at all, he would be financially eligible for all CSHCN services, although his family would have to pay a small fee. The program, however, does not provide skilled shift nursing or other extended home care services. It would cover only "M"'s physician visits, equipment, supplies, and medication.

Case 3: "T"

"T" was diagnosed at birth as having short gut syndrome and malabsorption. Now age 6, he has been hospitalized approximately 20 times for varying periods. When at home, "T" attends school regularly with a nurse. His daily home care requirements include 20 hours of intravenous nutrients, care of the central line, and frequent monitoring of his

glucose level. The monthly cost of his care is $17,035 ($10,000 for nutritional supplies, $7,000 for nursing, and $35 for a physician visit).

"T"'s parents, who have three children, both are employed full time and have a combined annual salary of $52,000. They have $6,500 in the bank, two cars, and are paying off the mortgage on their home. "T"'s hospital and home care both had been covered under his father's company insurance plan, but the family recently reached the $1,000,000 lifetime benefit maximum.

Medicaid Services

"T" cannot become eligible for Medicaid in Missouri, where the medically needy are not covered, but in the other four States he could become eligible as a medically needy recipient. His parents, however, would have to reduce their savings and incur very substantial medical expenses in order for him to qualify. The actual amounts would vary from State to State:

- in California, the family first would have to reduce its savings to $3,000 and then spend $2,405 for medical care each month to become eligible;
- in Georgia, the family first would have to reduce its savings to $2,700 and then spend $16,332 in each 6-month period before becoming eligible (an average of $2,722 per month); and
- in Kansas, the family first would have to reduce its savings to $1,700 and then spend $15,438 in each 6-month period (an average of $2,573 per month).[22]

Spend-down requirements of this magnitude (ranging from $28,860 to $32,664 annually) obviously would place an enormous financial burden on the family. Only in Maryland could "T" be brought into the Medicaid program without his family first having to meet the spend-down requirement, because under Maryland's model waiver "T"'s family income would not be deemed available to him.

Georgia operates three model waiver programs, but "T"'s condition is not covered by any of them. Having amended its State plan, Georgia also provides Medicaid to certain children who, because of the deeming rules, otherwise would be eligible only in an institution. Under this provision, though, the State restricts eligibility to children whose home care costs would be less than the cost in an SNF or ICF, and "T" would not qualify.[23] In California, "T" could participate in the regular waiver program, but since the SSI deeming rules would not be waived, "T" would be eligible for the program only after his family met the medically needy standard. Both California and Maryland offer parenteral nutrition as a regular Medicaid benefit and provide skilled shift nursing care as a waivered service.

In the two States where "T" could receive only non waivered services, his chances for adequate benefit coverage would differ dramatically. Kansas covers all necessary treatment services for children through its EPSDT program, which is not subject to the service limits of its regular Medicaid plan. Thus, after an initial screening, "T"'s parenteral nutrition and skilled nursing care both could be authorized under EPSDT.[24] Georgia, in contrast, does not use EPSDT to expand coverage for treatment services beyond what is regularly available under the State plan. "T" would be covered for the intravenous equipment, physician visits, and rehospitalizations, but not for his nutritional products or skilled shift nursing care.

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[22] These spend-down figures are based on the SSI eligibility determination methodology and each State's medically needy income level (MNIL) for one person. (The family's monthly income and an estimated $30 in bank interest were added together, $336 was subtracted as a living allowance for the other two children, $1,008 was subtracted as a living allowance for the parents, and $65 plus $20 was subtracted as an exclusion from the parent's earned income. The remainder, minus a $20 exclusion, was deemed available to the disabled child. Then each State's MNIL for one person was applied, as appropriate, on a 1-month or 6-month basis.)

None of the State Medicaid agency staff contacted by Fox and Yoshpe (59) would have followed the SSI methodology as it is prescribed by the Social Security Administration. In fact, one of the States would have used its AFDC methodology. Of the three that would have used the SSI methodology, two would have used a different methodology appropriate when no other children are in the family, two would have used the MNIL for either a three- or five-person family, and none would have included the unearned bank interest income.

[23] Georgia uses a maximum monthly home care service limit of $1,200 in determining an individual child's eligibility.

[24] Kansas uses a standard of $240 per day. However, since total parenteral nutrition would be an additional inpatient hospital cost, it would be calculated as an additional home care cost above the maximum day rate.

CSHCN Support

CSHCN programs in three of the States—Kansas, Maryland, and Missouri—provide case management and family training services to technology-dependent children enrolled in Medicaid. "T"'s family, therefore, could receive these services in Kansas and Maryland, where he would qualify for Medicaid coverage.

In California and Kansas, where SSI deeming rules could not be waived, "T" would need case management and any other available CSHCN services prior to meeting the Medicaid spend-down requirement. In California, the CSHCN program could purchase "T"'s equipment and parenteral nutrition, deliver 3 months of skilled shift nursing care, and provide continuous case management support; his family would be charged an amount equal to two times their State income tax. In Kansas, though, CSHCN covered services—which include many of the services "T" needs—are available only to children whose family income falls below the poverty line or who are eligible for Medicaid. "T" could not receive these services during the spend-down period.

CSHCN services in Georgia, not unlike many other States, do not include any high-cost home care services. If "T" and his family lived in Georgia, therefore, they could not depend on either Medicaid or the CSHCN program to finance, even partially, the skilled shift nursing care that "T" requires.

Unfortunately, in Missouri, where "T" has no opportunity at all for Medicaid coverage, he also would have no way of obtaining home care services through CSHCN. The program, like Georgia's, emphasizes treatment of crippling conditions and, while it has purchased sophisticated equipment on occasion, "T"'s family would be financially ineligible even for this benefit. The annual income cut-off for a family of four is $19,000.

DEPARTMENT OF DEFENSE

The Department of Defense (DOD) provides medical care, or payment for medical care, to the dependents of active and retired military personnel. It does so in two ways: through its own hospitals, operated independently through each of the four Armed Services branches; and through CHAMPUS, which pays for care that cannot be obtained in the military hospitals. Armed services hospitals and CHAMPUS are operated independently of one another, but they provide access to the same general categories of services.

DOD pays for nonhospital long-term care in two ways. First are the regular home health benefits available under CHAMPUS. These benefits include:

- durable medical equipment, including ventilators;
- oxygen;
- parenteral and enteral nutrition therapies;
- physical therapy;
- skilled nursing care;
- medications and medical supplies; and
- physician visits.

Many technology-dependent children, however, may not be judged eligible for the full extent of these home benefits, however, because *neither military hospitals nor CHAMPUS may provide, or pay for, "custodial care"* (164). CHAMPUS's policy manual defines "custodial care" as care rendered to a patient:

1. who has a mental or physical disability that is expected to be prolonged;
2. who requires a protected, monitored, or controlled environment, whether in an institution or in the home;
3. who requires assistance to support the essentials of daily living; and
4. who is not under active treatment that will reduce the disability to the extent necessary to enable the patient to function outside the protected environment (164).

If a military hospital (for a hospitalized child) or a CHAMPUS intermediary should determine that a technology-dependent child fits this definition, that child is then eligible only for a subset of the usual home benefits. These limited benefits include medications and medical supplies and up to 1 hour per day of nursing care.

CHAMPUS began a home care demonstration program on July 1, 1986, under which it provides extensive home care benefits (including 100 percent coverage of most costs and coverage of homemaker services) to patients who would otherwise be receiving hospital care. These patients could include children receiving intravenous drug therapy and many infants who can gradually be weaned from their dependence on respiratory or nutritional support. However, a child "must be receiving inpatient hospital care that is an otherwise authorized CHAMPUS benefit" in order to be eligible for the program (51 FR 23809). This provision still could exclude many technology-dependent children under current policy.

A second source of long-term care coverage is the Program for the Handicapped (PFTH), a special CHAMPUS benefit for handicapped dependents of military personnel. In order to receive benefits under this program, an individual must show that he or she cannot get services from public programs or institutions. Prior approval is required for coverage of all supplies and services under the program (164). PFTH covers institutional, outpatient, and home care but pays a maximum of only $1,000 per month in benefits (164). In addition to those supplies and equipment covered under the basic program, it covers physical, occupational, and speech therapy and special educational services. Skilled shift nursing and homemaker services are not covered. PFTH, like the regular benefits program, does not cover custodial care.

OTHER PUBLIC PROGRAMS AND SERVICES

A wide variety of programs and services financed by Federal or State governments can affect the resources and services available to technology-dependent children. For example, the Federal Government provides SSI maintenance payments to disabled individuals, and it provides certain adoption and foster care incentive payments to assist in finding homes for needy children (159). States can, and often do, supplement these payments with their own. For example, most States provide supplemental payments to foster parents who provide care for handicapped or other children with special needs (159).

Certain in-home services, funded jointly by the States and by Federal Title XX social service block grants (Public Law 97-35), may be provided to low-income disabled individuals. Title XX funds are provided to States in order to prevent or remedy abuse of children and other family members; reduce inappropriate institutional care; secure admissions to and services in institutions when such a setting is appropriate; and prevent or moderate the dependence of individuals on other persons (159). Services may include homemaker, home health aide, and other basic home services (e.g., transportation) that can supplement the home-based medical services available through Medicaid.

States may also have their own special programs, funded entirely through State and local taxes, that provide special benefits to targeted groups. Wisconsin, for example, has a State program that provides "gap-filling" funds to individuals, including children, who are at risk of institutionalization. Wisconsin also has a family support program that provides, separately from SSI, up to $3,000 per year cash assistance to families with severely disabled children living at home (37). This example demonstrates that the resources available to a child can be enormously varied, depending on where the child lives—and on the access of that child's family to appropriate information and coordination of services.

CHARITABLE ORGANIZATIONS

Charitable organizations have long been visible sources of research and services to aid the disabled. About 20 national children's health charities operate in this field, ranging in size from very large organizations such as the National Easter Seal Society to small organizations such as the Retinitis Pigmentosa Foundation (117). The missions, disease orientations, and structures of the various charities are similarly diverse. The majority of national charitable organizations focus their efforts on one disease or closely associated set of diseases. However, an organization may concentrate on research, public education and political lobbying, direct provision of services, family education and support, or any of a number of other activities.

Charitable organizations have functioned as last-resort providers for many families with technology-dependent children. One of their most important functions in this regard is as a provider of family support and education. Table 25 lists the expenses of selected foundations for various services, including medical services and patient education. Spending for these services range from 15 percent of expenditures (March of Dimes) to 92 percent of expenditures (Easter Seal Society) (27). "There is no strong relationship between prevalence of a chronic condition and relative magnitude of foundation support. . . . Consequently, children with certain disabilities have more resource available to them than others" (27). Researchers who interviewed a number of national charitable organizations concluded:

> Although foundations expend a significant amount on direct services, they tend to provide assistance to cover only those services that are not otherwise reimbursable and that place an unreasonable financial strain on families with disabled children. These services included transportation, educational and recreational activities, physicial and occupational therapy, special medical equipment, and to a lesser extent, medical care (27).

Table 25.—Total Amount of Expenses Allocated for Programs of Selected Foundations, 1979 and 1980 (millions of dollars)

Private foundation	Total program services	Research	Medical services and patient education	Public and professional education	Community services/advocacy
Muscular Dystrophy Association, 1979	$56.6	$18.0	$33.3	$5.3	—
March of Dimes, 1980	49.9	10.2	7.6	18.4	$13.6
Cystic Fibrosis Foundation, 1980	11.1	1.7	4.2	3.6	1.5
American Diabetes Association, 1980	9.7	1.7	2.7	3.6	1.7
Arthritis Foundation, 1980	6.0	2.9	[a]	2.3	0.8[a]
Leukemia Society of America, 1980	3.9	2.2	1.0	0.5	0.2
American Kidney Fund, 1979	1.5	0.04	0.9	0.2	0.4
Easter Seal Society, 1979[b]	85.7	0.5	79.1	6.1	—

[a] The Arthritis Foundation combines patient and community services into one category.

[b] The Easter Seal Society includes the combined expenditures for the national and all State and territorial Easter Seal Societies.

SOURCE: J.A. Butler, P. Budetti, M.A. McManus, et al., "Health Care Expenditures for Children With Chronic Illnesses." *In:* N. Hobbs and J.M. Perrin (eds.), *Issues in the Care of Children With Chronic Illness* (San Francisco, CA: Jossey-Bass, 1985).

CONCLUSIONS

It is impossible to provide any accurate estimate of the proportion of technology-dependent children with private insurance whose insurance coverage includes intensive home care benefits, but it is possible to get a sense of how likely comprehensive coverage is. Although private health insurance is a major source of third-party payment for children, as presently structured it is inadequate to provide for the needs of technology-dependent children. It fails in several ways. First, many children are left uninsured as a result of their families' economic positions. Second, some technology-dependent children may find it difficult or impossible to obtain private insurance. Third, even those children who are privately insured have coverage that is likely to be inadequate to cover the expenses associated with these medical conditions. Finally, the structure of benefits under many policies is too rigid to deal with the needs of technology-dependent children when they are cared for in the home. Parents whose children require full-time monitoring and medical care dare not give up employment to provide some of this care, and yet in the majority of cases their insurance will not pay for a qualified professional caretaker.

Notwithstanding the seriousness of the current insurance situation for these families, the private insurance industry has made strides over the past 5 years towards accommodating payment systems to complex medical care in the home setting. It has done so primarily through case-by-case exception to normal home coverage limits.

The willingness of private insurers to provide at least case-by-case exception is vital to both beneficiaries and to public payers, because many technology-dependent children quickly lose their private benefits by reaching the maximum allowable benefit amount. The longer these children can stretch out private insurance through home care, the longer they have before they become dependent on Medicaid for health insurance.

Medicaid has likewise made some progress in the past few years towards accommodating this population. Showing cost savings to Medicaid by caring for a technology-dependent child at home is by no means impossible, and the current waiver programs have shown considerable success at serving at least a few children in this setting at less cost to the program. It is, however, generally much more difficult to show cost savings to Medicaid than cost savings to a private insurer, because Medicaid pays much less in the hospital. States have attempted to limit home and community costs by restricting eligibility or services in some cases. Unfortunately, the exclusion of certain expensive services—particularly skilled shift nursing—can absolutely prevent many technology-dependent children from coming home.

DOD has found it more difficult than Medicaid to adapt its payment system and benefits to technology-dependent children. While the usual home benefits under CHAMPUS can be substantial, those benefits are not available to a technology-dependent child who is judged to need very prolonged, supportive care. Unless the regulations defining custodial care are changed, or the military hospitals and CHAMPUS undertake a much more liberal interpretation of the regulations when the prolonged care is very complex, long-term home care benefits for many technology-dependent children are unlikely to be forthcoming.

To the CSHCN programs in many States, the complex needs of nonhospitalized technology-dependent children offer a new opportunity to be a primary player in a significant health care issue. These programs have often acted as advocates for their clientele in the past, and they now have a significant new role to play as coordinators of payment and community services to this group of disabled children. The degree to which the programs are prepared to play this role, and their proficiency at it, undoubtedly varies from State to State. But the role seems an appropriate one, and it may give many of the programs new purpose and direction.

It is very possible that the extension of private and public insurance benefits into the home care setting will replace charity care to some extent. Charitable organizations, including local community and religious organizations, have helped many children obtain certain equipment and facility renovation. However, care coordination and skilled shift nursing have never been the province of charitable organizations, and these are the areas in which improved health insurance benefits are most likely to have an impact.

None of the solutions being implemented at the moment regarding technology-dependent children are applicable to children who will, due to some medical or home characteristic, be more expensive to care for at home than in the hospital. For some such children, home care may be the most effective and desirable even if it is not the least expensive. For other children, however, particularly those without a supportive family, other care alternatives will be necessary. Unfortunately, at present, appropriate and effective long-term care options other than the family home and the hospital are extremely rare.

Appendixes

Appendix A

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Appendix B

Workshop on Technology-Dependent Children

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Agenda
Workshop on Technology-Dependent Children

Office of Technology Assessment
600 Pennsylvania Avenue, S.E.
Washington, D.C.
April 11, 1986

9:00 Refreshments
9:15 Opening remarks
  Clyde Behney, OTA Health Program Manager
  Judith Wagner, Project Director, Technologies and Child Health
  Elaine Power, Study Director, Technology Dependent Children
9:30 Defining the population of technology-dependent children
  - discussion of economic implications of alternative definitions for children, providers, payers
  - current research on definitions
  - potentially useful combinations of candidate definitions
  - definitions not included in candidate list
  - the place of case-by-case review in defining for Medicaid eligibility purposes

11:00 Break
11:15 Defining the population (continued)
  - discussion of criteria for judging definitions
  - assessment of candidate definitions according to criteria

12:30 Lunch
1:30 Data sources
  - approaches to getting data
  - programs, offices, states, etc. collecting data on this group

2:00 Changes in the technology-dependent population
  - current evidence on trends
  - changes due to extension of current technology (e.g., more NICUs, trauma centers, extended access to treatments)
  - changes due to new technologies (e.g., artificial surfactants)
  - apparent changes due to the new availability of home services

4:00 Summary and closing remarks

Appendix C

Implications of the Population Definition

Introduction

The way the population of technology-dependent children is defined and enumerated has clear implications for the costs to third-party payers of paying for care, and the access of these children to different care alternatives. The broader the definition, the larger the number of children who may become eligible for special benefits. Providing enhanced insurance coverage for technology-dependent children may itself lead to an increase in the size of the population, through encouragement of more aggressive medical practices.

The definition of technology dependence presented in Chapter 2 was developed for the purpose of enumerating the population, not for describing it for insurance or program eligibility purposes. These two definitional purposes overlap to some extent, but they can also conflict. The pragmatic, data-based definition applied in this technical memorandum would be inappropriate if applied in a program context without other considerations. To be applied appropriately to eligibility, a definition of technology dependence must take into consideration the following questions:

- Does the definition include all children who would reasonably be considered to be technology dependent?
- Is the definition flexible, or would it need to be revised frequently to accommodate new groups of deserving children?
- Can the definition identify children with similar needs for health care, so that they can receive the same level of benefits (horizontal equity); and can it distinguish those with greater need from those with lesser need (vertical equity)?
- Can the definition distinguish between children for whom home care is less expensive than institutional care from those for whom it is more expensive (possibly because the child would not be institutionalized even in the absence of home care benefits)?
- Is the definition compatible with distinguishing children for whom home or community-based care is feasible and desirable, and can it provide a basis for estimating the cost of services provided in these environments?

Three potential specific approaches to identifying the population are to use: 1) diagnosis, 2) functional limitation, or 3) medical services needed. These approaches are not necessarily mutually exclusive, but their benefits and drawbacks can be discussed separately from one another.

Three Alternative Approaches

Definition Based on Diagnoses

Diagnoses could be used as a basis for identifying children as technology dependent, an approach that has two attractions. First, in most cases diagnoses provide distinct and verifiable information. Second, diagnostic data on hospitalized patients are regularly collected and analyzed on a national basis.[1] A definition of technology dependence based on diagnosis could be specific (e.g., bronchopulmonary dysplasia) or broad (e.g., any chronic lung disease).

There are a number of serious problems with using this approach. First, there is not a one-to-one correspondence between diagnoses and the need for long-term intensive nursing care. Table 26 lists a few of the many diseases (some of them very rare) that can lead to life-sustaining dependence on respiratory or nutritional support. Maintaining a comprehensive list might be very difficult, preventing some technology-dependent children from being included. Also, only a small proportion of the children with these diseases require prolonged technology supports. For example, of children with muscular dystrophy or cystic fibrosis, only those in the later stages require ventilators or even less intensive respiratory support such as frequent suctioning and oxygen (4,79). Thus, any definition that includes diagnostic criteria must rely heavily on other criteria as well.

Defining the population based on broader categories of diagnoses or disorders would be considerably less cumbersome but correspondingly less specific. It, too, would produce categories that are larger, probably many times larger, than the population of children that is usually institutionalized and is dependent on life-sustaining medical devices.

Definition Based on Functional Limitation

Identifying disabled people, particularly the elderly, according to their functional limitations and their ability to carry out certain activities of daily living has been common for some time. Activity limitation questionnaires have been used in surveys to provide na-

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[1] Diagnoses are coded onto hospital discharge abstracts, according to the conventions of the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) coding system. These codes and other information from discharge abstracts are then maintained, summarized, and analyzed by a number of different government and private organizations.

Table 26.—Some Conditions That Can Lead to Dependence on Respiratory or Nutritional Support

Conditions that can lead to dependence on respiratory support:
brainstem aneurysm
bronchopulmonary dysplasia
central hypoventilation syndrome (Ondine's curse)
congenital heart disease
cystic fibrosis
Ellis-van Creveld syndrome
encephalitis
interrupted phrenic nerves
multiple sclerosis
muscular dystrophy
myelodysplasia
near-drowning
nemaline rod myopathy
neonatal asphyxia
Pierre-Robin syndrome
Pompe's disease
radiation lung damage
severe head injury
spinal muscular atrophy
subglottic stenosis
upper spinal cord injury
Werdnig-Hoffman disease

Conditions that can lead to dependence on nutritional support:
Alagielle's syndrome
chronic diarrhea
congenital bowel defect
cystic fibrosis
failure to thrive
inflammatory bowel disease
ischemic bowel disease
liver disease
milk/soy protein intolerance
motility disorder
necrotizing enterocolitis
neoplasms
neurological disorders of swallowing
radiation enteritis

NOTE: These diagnoses constitute only a partial list of conditions that can lead to dependence on respiratory or nutritional support. Conditions listed here are actual diagnoses of children using these technologies, as recorded in a national nutritional support database and a summary of children served by special Title V programs in three States in 1985.

SOURCES: L. Heaphey, The Oley Foundation, Albany, NY, personal communication, Aug. 21, 1986; [illegible] Aitken and L.A. Aday, "Home Care for the Chronically Ill and/or Technology Assisted Child: An Evaluation Model," unpublished, November 1985.

tional estimates of disability prevalence and severity in the population (63) and in studies of resource utilization among nursing home residents (133,140,182). Scales to measure activity limitation are relatively well developed and seem to be good predictors of the intensity of required nursing and personal care services for many elderly and disabled people.

The main limitations of these scales are that each person must be assessed individually and frequently, which is time-consuming and leaves considerable discretion to the assessor; and the scales are not well suited to identifying the specific skilled nursing services an individual may need.[2]

Another approach could be to identify children by the limitations of their normal body functions, such as eating or breathing. This approach (the one used in this technical memorandum) has intuitive appeal, because it would identify those children who use specific technologies that replace or compensate for normal body functions. The limitation of this approach is the difficulty in distinguishing levels of care needed in conjunction with the various technologies.

Definition Based on Type or Amount of Services Needed

A third approach might be to identify technology-dependent children by the type or amount of medical services they require. This might take the form of defining the population according to the need for certain nursing services, such as catheterization. Or, it might take the form of an indirect but explicit indication of level of services needed, such as prior institutionalization or time in a neonatal intensive care unit. Finally, the population might be identified by the type of long-term care plan required by its members. For example, the defined population might include children whose documented care plans specify hospice care and long-term chronic, continuous care, but not children requiring intermittent monitoring, occasional crisis care, or post-acute, recuperative care.

Considerations in Applying the Definition

Within the group of children identified as technology dependent, there will exist considerable variation in health and social needs. Ideally, an appropriate definition should be able to be applied in such a way that differences in need among children can be discerned, with appropriate differences in benefits provided to them. For example, two children might be equally ventilator dependent, but one might be able to dress and feed himself while the other cannot. This example emphasizes the value of functional assessment in applying a definition equitably.

Home care may be feasible and desirable, but not cheaper than institutional care, for some children. If these children are to be included, the definition should have a mechanism for detecting those children for whom the medical, psychological, and developmental benefits of home care are high in relation to the additional costs of home care. This criterion again implies that the definition should include some indication of relative need and prognosis over time. A child with a long-term or terminal illness, for example, might benefit more from the psychological and social aspects of home care than a child recovering rapidly from an acute condition, and consequently it might be desirable to be able to distinguish the former child from the latter for the purposes of providing benefits.

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[2] Although there is considerable experience in applying specific assessments of a person's ability to function, few of these applications have assessed any limitations in basic body functions that require nursing skills (e.g., the need for colostomy care). One survey that includes these categories is currently being conducted on children with six types of disability and chronic illness (73).

Meeting a particular definition need not necessarily imply absolute access to a special program or set of benefits. A definition can also be thought of as a screening mechanism to most easily identify the bulk of children who would benefit from extensive individual assessment and a particular set of services. One possibility is that some fairly rigid, easily identified characteristics be used for rapid screening purposes, but that actual eligibility for benefits be dependent on the child's functional or nursing assessment score, where activity limitations, degree of independence capability, and limitations of body functions are all evaluated.

Appendix D

Alternative Settings of Care

Introduction

Most of the public discussion surrounding technology-dependent children, and most of the evidence discussed in this technical memorandum contrasts two settings of care for these children: hospital care, usually in an acute-care[1] hospital; and home care with the children's natural families. Within acute-care hospitals, technology-dependent children have access to the full spectrum of medical services and equipment, monitoring, intensive nursing, professional backup, and emergency services that can be mobilized immediately. The children typically reside in intensive care units or specialty wards (e.g., burn units), but they may reside in general nursing wards (for children not requiring mechanical ventilation) or, sometimes, "step-down" transitional care wards.

In contrast to acute-level hospital care, home care offers an environment most nearly like those in which non-technology-dependent children grow up. From the perspective of third-party payers of health care, traditional home care offers the financial advantage of basic living expenses that are borne by families. Many technology-dependent children currently living at home have highly trained and motivated parents and other caregivers, whose time attending the child is also free to the payer. At home, unlike in an institution, the needed quantity of some services—e.g., the number of paid nursing hours or the amount of respite care—depend as much on the social, psychological, and financial characteristics of the family as on the physical condition of the child.

As more payers finance and perhaps even emphasize nonhospital care, other settings of care may also become important for technology-dependent children. These alternative settings of care may serve three possible purposes:

1. *Transitional care* for children who are moving from hospital to home or other long-term care. Transitional care is appropriate after the child has become medically stable, while the home (or other setting) is being prepared for the child and the myriad of financial and administrative details are being completed. It usually includes an emphasis on training the family and gradually increasing the care the family provides. Transitional care can be provided in a special hospital unit or in a separate rehabilitative or subacute care facility.
2. *Respite care* for technology-dependent children who are living at home. Institutional or foster home respite care may be an important option in situations where qualified professional nurses are not available for home respite care, or where a family vacation or emergency might make the home an inappropriate setting of care for a short period of time.
3. *Long-term care* for children whose parents are unwilling to have them home, negligent, abusive, or simply unable to cope with them. Extensive supportive home services and counseling may help parents cope with having a technology-dependent child at home. Even so, there will be a small group of children for whom care settings other than a natural home must be explored as a long-term option.

A Michigan task force on home care guidelines for ventilator-dependent children summarized the need for these three types of options as follows:

> As the child's condition stabilizes, there should be progression from the intensive care setting to one of habilitation/rehabilitation and eventually to a home-like environment. If the home is not a short or long term option for care, alternative, home-like situations such as foster homes and small group homes must be explored. Such institutional alternatives must always remain an option to avoid crisis when home care ceases to be feasible or is not longer the best option for the responaut [ventilator-dependent child], family, community and fiscal agencies (114).

Foster and Adoptive Care

For technology-dependent children who cannot return to their natural family home (temporarily or long-term), a foster or adoptive home may become the setting of choice. If home care services and financing become more accessible to children whose families are able and willing to accept them and help care for them, children needing foster or adoptive homes are likely to become a growing proportion of the residual institutionalized population.

Foster home need is likely to be greater among this population than the child population in general, because in addition to the need to find homes for children with incompetent or abusive parents, there is a need to find homes for technology-dependent children whose parents simply cannot accept their extensive disabilities. Furthermore, technology-dependent children are considered to be harder to place in foster homes than other children. A concerted drive to serve all technology-dependent children at home would soon run up against a shortage of available foster homes.

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[1] "Acute-care hospital" as used here means a hospital that provides complex medical care to patients and has an average length of patient stay of less than 30 days.

A lack of foster and adoptive homes may become an equal or greater barrier to home care than a lack of sufficient home medical care benefits. The total number of foster care homes in the United States dropped from 594,000 in 1977 to 187,680 in 1984, attributed in part to greater efforts to keep children with their natural parents (the number of foster children has dropped from roughly 500,000 in the late 1970s to roughly 250,000 in 1984) but also to a greater drop in families willing to take in foster children (77,90).

The Federal Government provides matching subsidies with the States to families who adopt children with special needs, as well as to those families who provide them with foster homes (Public Law 96-272). Children in both categories for whom Federal subsidies are provided are automatically eligible for Medicaid. Ironically, those same children may *not* be eligible for Medicaid if they remain with their natural families.

Community Group Homes[2]

The group home provides a community-based option, midway between institutionalization and a family home, that could be attractive for some technology-dependent children if it were available. Group homes for adults who are ventilator-dependent due to polio have existed in England and France for a number of years (67), and a few similar group homes have recently opened in California (115), though apparently none are accepting young children at present. Louisiana is considering the establishment of a group home that could accommodate ventilator-dependent children as well as other developmentally disabled children (97).

For some children, the costs of group home care might actually be lower than either hospital or family home care because a single trained nurse might be able to care for more than one technology-dependent child. However, OTA knows of no present examples of group homes that accept, or were designed for, technology-dependent children. The relative rarity of such children in the population suggests that group homes organized for this purpose would probably be practical solutions only in densely populated areas.

Institutional Settings of Care

With appropriate enhancement of facilities and staff, a multitude of subacute institutional settings could be appropriate for many technology-dependent children who cannot, for whatever reason, be placed in home care. None of these are likely to be appropriate for all such children, nor are they likely to be preferred over hospital care (e.g., in a special long-term care unit) in all cases. But they may well be appropriate options for a proportion of the population. Unfortunately, even when they might be appropriate, they are likely to be unavailable.

Hospital Settings

Some acute-care hospitals have "step-down" units with the capacity for intensive care but an emphasis on transition to a less intensive setting. A few hospitals have experimented with special wards in which the parent cares for the child during part or all of the day (51,119).

A fairly recent phenomenon is the development of special pediatric respiratory centers, focused specifically on the long-term care needs of medically stable, ventilator-dependent children. Such centers may be in acute-care tertiary hospitals, or in chronic care and rehabilitation hospitals. In both cases, the centers have generally been developed as "step-down" units that serve the needs of ventilator-dependent children (and their families) in the transition to long-term community-based care. However, in practice many children live on such wards indefinitely.

Children's Hospital of Philadelphia has one of the best-known pediatric respiratory units in an acute-care hospital. Similar units exist at a few other acute and long-term care hospitals, though not all are exclusively pediatric.[3] Ranchos Los Amigos Hospital, for example, a rehabilitation hospital that serves some children as well as adults, first established a special respiratory unit in 1952 to better serve its long-term polio patients on respirators (2). Other pediatric respiratory units and intensive care units in extended-care hospitals exist (e.g., in Chicago, IL; Pittsburgh, PA; Washington, DC; and Baltimore, MD) or are being contemplated, but they are still rare.

Skilled Nursing and Intermediate Care Facilities

Skilled nursing facilities (SNFs) are an important source of care for many elderly, chronically ill people, but they do not generally have sufficient staff to provide intensive nursing services and usually do not provide an environment conducive to pediatric care and child development. The children most likely to be found in SNFs, where they are accepted at all, are those who are comatose or have low mobility but few constant skilled medical needs—perhaps daily medications or, at most, the need for multiple daily tube feedings (97). Intermediate care facilities (ICFs) are more likely to care for children, but they are even less likely to be able to provide intensive medical care than SNFs.

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[2] Many group homes are apparently regulated as foster homes.

[3] The distinction between rehabilitation, chronic care, and other types of long-term care hospitals is largely one of self-definition, associated with how a hospital sees its mission. It is not clear that rehabilitation hospitals are more likely than chronic care hospitals (or vice versa) to establish respiratory units.

SNFs do sometimes accept technology-dependent adults. For instance, a 1985 survey of ventilator-dependent patients in long-term care facilities in Pennsylvania documented 55 such patients in 4 nursing homes and 1 skilled/intermediate care facility, all of whom were adults (94). Likewise, a few SNFs in California accept ventilator-dependent patients, but none are known to accept such patients under age 16 (115).

At least two SNFs in the United States (one in New Jersey and one in Ohio) are equipped to serve children exclusively and can provide the complex care needed by technology-dependent children (139). In many ways, these SNFs are more similar to pediatric long-term care hospitals than they are to geriatric SNFs. For example, the pediatric SNF in New Jersey is staffed to provide 6.5 nursing hours per patient per day, almost three times the nursing intensity provided in geriatric SNFs in that State (139).

A trend towards making SNFs a more common site of care for ventilator-dependent individuals and other individuals (not necessarily children) needing post-acute complex care seems to be taking place. Three States have recently proposed or established regulations for "super-SNF" subacute care, and at least 13 others have instituted some reforms that can allow for extra payments to nursing homes for complex care patients (88). California, for example, has proposed regulations that will enable its Medicaid program to pay for care in specially certified SNF units that have a higher level of nursing intensity and skill than normal SNF care (30). These subacute units will receive a higher per diem rate than the usual SNF rate. A description of California's subacute care regulations is presented in box E.

ICFs are less oriented toward complex medical care than SNFs, and they are thus even less likely to accept technology-dependent patients or to be able to provide them with comprehensive care. ICFs are typically institutions in which most residents require relatively little skilled nursing but considerable custodial care (e.g., dressing, feeding, bathing, or just frequent attention). Homes for the mentally retarded are probably the most familiar form of ICFs. There may be a few technology-dependent children who are alert but need a highly protected environment and for whom an ICF with enhanced services and staff might be an appropriate setting.

Box E.—Medicaid Coverage of Subacute Care in California

California has recently confronted the problem of appropriate institutional placement (and payment) for technology-dependent persons when home care is not feasible. On August 19, 1986, the State held public hearings on proposed Medicaid regulations establishing a category of subacute care in skilled nursing facilities (SNFs). (As of March 1987, it appeared that the Health Care Financing Administration will allow California to implement these regulations, but Federal approval was not yet final.) The revised text of the proposed regulations adopts additions to State Medicaid regulations, as follows.

Definition.—"Subacute level of care means a level of care needed by a patient who does not require acute care but who requires more intensive licensed skilled nursing care than is provided to the majority of patients in a skilled nursing facility." A subacute care unit is "an identifiable unit of a skilled nursing facility accommodating beds including contiguous rooms, a wing, a floor, or a building that is approved by the Department for such purpose" (30). Subacute care units are subject to all of the State certification and licensing requirements applicable to skilled nursing facilities. They may be in hospital-based or freestanding SNFs.

Staffing.—"Subacute care units shall employ sufficient licensed staff to provide a minimum daily average of 4.8 actual licensed nursing hours per patient day for non ventilator dependent patients, and a minimum daily average of 6.2 actual licensed nursing hours per patient day for ventilator dependent patients" (30). At least one registered nurse (RN) and one licensed vocational nurse (LVN) must be on each shift, and the ratio of LVNs to RNs cannot exceed 4 to 1. Both RNs and LVNs must have prior acute care experience. The unit must be able to provide, within the institution or through contract, laboratory, X-ray, respiratory therapy, and pharmacy services.

Services.—The proposed regulations define subacute care services as "a type of skilled nursing facility service which is provided by a subacute care unit" (30). Patients must be under the care of a physician who makes frequent visits and must have 24-hour access to services in an acute-care hospital. They must require special supplies or equipment, 24-hour nursing, and administration of three or more of the following treatment procedures:

1. traction and pin care for fractures;
2. total parenteral nutrition;
3. inpatient physical, occupational, and/or speech therapy, at least 2 hours per day, 5 days per week;
4. tube feeding;
5. tracheostomy care with suctioning;
6. oxygen therapy and/or inhalation therapy treatments at least four times per day;
7. continuous or frequent intravenous therapy via a peripheral and/or central line;
8. medically necessary isolation;
9. debridement, packing, and medicated irrigation with or without whirlpool treatment; and
10. continuous mechanical ventilation for at least 50 percent of each day (30).

Medicaid Payment.—The State calculated payment amounts for these new subacute facilities based on hourly costs of nursing care and facility costs reported by SNFs, adjusted by the more intense nursing requirements of the subacute care units and predicted higher use of supplies and electricity (29). The resultant recommended maximum daily rates for SNF subacute level of care were:

- $221.93 for ventilator-dependent patients in hospital-based units,
- $187.71 for other eligible patients in hospital-based units,
- $140.62 for ventilator-dependent patients in freestanding units, and
- $109.62 for other eligible patients in freestanding units.

Appendix E

The Educational System as a Source of Health Care Services and Funding

Introduction

An important aspect of the cost of care for technology-dependent children in the home setting is that substantial portions of this cost may be borne by public schools. Public schools are mandated by Federal law to provide educational and necessary related supportive services to handicapped children (Public Law 94-142). Schools, through special education programs, regularly provide medical services such as physical and speech therapy, medication administration, and even urinary catheterization to children (179). Since school attendance may account for more than one-fourth of a child's time and care needs, one consequence for technology-dependent children of this Federal mandate is to shift substantial portions of the cost of a child's medical care services from Federal to State and local governments (i.e., from Medicaid to public schools), and from private health insurers to the public.

The issue of who will pay for the medical care of these children in the schools is a growing one. Public schools, pressed for funds, may often be reluctant to pay for additional full-time nurses and special transportation vehicles and to assume legal liability for medical care during school hours. At the same time, private insurers—and Medicaid—will seek to minimize their costs of serving technology-dependent children at home by shifting financial responsibility to the schools. School districts may respond by serving most of these children with occasional home visits in order to avoid the extraordinary nursing costs and potential lawsuits. Clear Federal and State policies on this issue could greatly aid in minimizing total costs, encouraging education in the environment most appropriate to the individual child, allocating public dollars appropriately (e.g., to Medicaid or to public school assistance), and preventing the emotional and financial stress of legal battles.

Local Options for Complex Medical Care in Schools

The issue of complex medical care for children attending public schools can be summarized in three questions:

1. Where is this care provided?
2. If it is provided in the school, who provides it?
3. If it is provided in the school, who pays for it?

For some children, such as those with frequent and uncontrollable seizures, home education may be the only feasible choice. In these cases, school districts may provide an individual teacher for a few hours a week in the child's own home. In such cases, the child's nursing needs are usually met by the normal home caregiver (a parent or home nurse), and reimbursement for that care is indistinguishable from reimbursement for the child's usual home care. The school system pays for the teacher's time and transportation.

Many technology-dependent children receive their education in special classes or schools. In some of these schools, nursing care is provided by full-time professional nurses. In others, the teachers themselves, or a classroom aide, may be trained to provide these services. In either case, the school system generally pays for the medical care, since the nurses or teachers are providing care to a number of children.

The third setting of care and education for a technology-dependent child is in a normal classroom. This setting is particularly appropriate for a child who is intellectually normal and has no mental or emotional constraints to maintaining a normal class schedule. However, the dilemmas regarding who shall provide, and pay for, the nursing care needed by a technology-dependent child are particularly acute in this setting.

Three options exist for providing nursing care in a normal school classroom. First, care may be provided by a school nurse. In most schools, a nurse provides services to all children, and the nurse may even serve more than one school. The school district is responsible for the salary of the nurse and any other costs associated with nursing services. Technology-dependent children, however, are characterized by their need for the uninterrupted availability of nursing services. For a school to provide such services, the school district must hire an additional full-time nurse or aide for each technology-dependent child in the district, as well as the regular nurse. Under this option, the insurer avoids all nursing costs during school hours.

A second option for providing care in a normal classroom is through a home nurse, whose salary and expenses are covered through Medicaid or another third-party payer, who accompanies the child while at school. Although the effect of this option is the same as the first—a full-time nurse for every technology-dependent child—it is clearly less desirable to the third-party payer, which must now pay the costs, and more desirable to the school district, which need not. If Medicaid is paying for home care, the nurse would be paid for through public funds in any case, but the source of the funds is administratively distinct.

A third option is to train teachers and other regular school personnel to provide the necessary nursing care. Louisiana, for example, has chosen to train bus drivers, teachers, school nurses, and principals to perform both routine and emergency procedures that might be needed by ventilator-dependent children (97). In this case the costs incurred are training costs, which may be paid by the district, the health insurer, or some other source, and possibly the costs of a smaller student-to-teacher ratio in the classes that include these children so that the teachers are not overburdened.

There are few Federal or State legal or administrative guidelines regarding who should pay for these nursing services in the schools, or how they should be provided. A survey of education and public health departments in all 50 States (but not the District of Columbia) regarding the provision of a specified list of nursing practices[1] found that 13 States (26 percent) had no written State guidelines regarding the provision of any of these services in the schools (184). An additional 13 States had guidelines only for medication administration. Only six States (12 percent) had guidelines covering all listed procedures. The remaining 18 States (36 percent) had written guidelines covering some, but not all, of the specified procedures. The lack of comprehensive guidelines in most States may reflect the fact that serving medically complex students is an issue that is usually addressed on the local rather than the State level (184).

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[1] The nursing practices included in the survey were catheterization, seizure management, medication administration, respiratory care, tube feeding, positioning, colostomy/ileostomy care, and other (including allergy shots).

Appendix F

Glossary of Terms and Acronyms

Glossary of Terms

Acute-care hospital: A hospital in which the average length of stay is less than 30 days.

Apnea monitor: A medical device that detects the cessation of breathing.

Asphyxia: Lack of oxygen resulting in suffocation or near-suffocation.

Augmented care: Care of a greater level, scope, or duration than that normally provided under a particular program or protocol.

Bronchopulmonary dysplasia: A chronic lung disease in newborns, often defined by a characteristic appearance of the lungs on X-ray and the need for mechanical ventilation for more than 4 weeks.

Case management: Coordination and oversight of the package of services provided to an individual. Case management may be provided by an insurer, a pediatrician, a parent, a social worker, or some other health care professional. The comprehensiveness of case management, and its goals, depend on the manager.

Cerebral palsy: A paralysis of varying severity that results from nonprogressive damage to the brain at or around birth.

Copayment: In insurance, a form of cost-sharing whereby the insured pays a specific amount at the point of service or use (e.g., $10 per visit). See also *Coinsurance*.

Coinsurance: That percentage of covered medical expenses, after subtraction of any deductible, for which an insured person is responsible. Under Medicare Part B, after the annual deductible has been met, Medicare will generally pay 80 percent of approved charges for covered services and supplies; the remaining 20 percent is the coinsurance, for which the beneficiary is liable. Also see *Copayment* and *Deductible*.

Colostomy: A surgical opening between the colon (part of the large intestine) and the surface of the body. A colostomy is perfomed when normal defecation is difficult (e.g., because of lack of control of the necessary muscles) or harmful.

Congenital: Present at birth. Congenital anomalies usually refer to birth defects that result from imperfect development during pregnancy.

Cystic Fibrosis: An inherited disorder caused by the production of a unique glycoprotein that results in abnormal mucous secretions. It is usually fatal before age 20. Death is due to excess mucus in the lungs and to pancreatic insufficiency.

Deductible: The amount of health care charges that an insured person must pay each year before he or she is eligible for coverage.

End stage renal disease: Chronic renal failure that occurs when an individual irreversibly loses a sufficient amount of kidney function so that life cannot be sustained without treatment. Chronic renal dialysis, kidney transplant surgery, and continuous ambulatory peritoneal dialysis are forms of therapy.

Gastrostomy: A surgical opening into the stomach. A gastrostomy tube allows food to be introduced directly to the stomach, bypassing the mouth and throat. A jejunostomy tube (which connects with the top of the large intestine) may also perform this function.

Hemophilia: A hereditary bleeding disorder distinguished by a deficiency of one or more blood coagulation factors—e.g., Factor VIII (hemophilia A) or Factor IX (hemophilia B).

Home health care: Medical and related services provided in the home.

Hospice care: Medical care rendered to terminally ill patients that is intended to be palliative rather than curative.

Ileostomy: A surgical opening between the ileum (the end portion of the small intestine) and the surface of the body. See also *colostomy*.

Incidence: The frequency of new occurrences of a condition within a defined time period, usually 1 year. Compare *prevalence*.

International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM): A two-part system of coding patient medical information used in abstracting systems and for classifying patients into DRGs for Medicare. The first part is a comprehensive list of diseases with corresponding codes compatible with the World Health Organization's list of disease codes. The second part contains procedure codes, independent of the disease codes.

Intravenous therapies: Nutrients, medications, or other treatments administered directly into the bloodstream (specifically, into a vein).

Long-term care: Health care of prolonged or indefinite duration. Long-term care hospitals usually have an average length of stay of 30 days or more.

Meconium aspiration: The existence of meconium, a dark substance normally found in the intestine of a full-term fetus, in the airway. Meconium aspiration can cause difficulties in breathing after birth.

Medical device: Any instrument, apparatus, or similar or related article that is intended to prevent, diagnose, mitigate, or treat disease or to affect the structure or function of the body.

Medical technology: The drugs, devices, and medical and surgical procedures used in medical care, and the organizational and support systems within which such care is provided.

Multiple sclerosis: A progressive, crippling disease of unknown cause that destroys the myelin sheath that insulates nerve cell axons. This results in slowed nerve conduction. Symptoms commonly include weakness, lack of coordination, and speech and visual disturbances.

Muscular dystrophy: A group of inherited neuromuscular diseases that result in the progressive deterioration of muscle function.

Neonatology: The medical specialty of newborn care.

Parenteral nutrition: The intake of nutrients directly into the bloodstream (intravenously), circumventing the digestive tract. Strictly speaking, intramuscular administration of nutrients is also parenteral nutrition, but the term as normally used in health care implies bloodstream administration.

Patent ductus arteriosus: Incomplete closing of a fetal blood vessel that allows blood that is low in oxygen to be returned to the body rather than to the lungs.

Phototherapy: The treatment of diseases, such as jaundice in newborns, with light.

Prevalence: In epidemiology, the number of cases of disease, infected persons, or persons with disabilities or some other condition, present at a particular time and in relation to the size of the population. Also called "prevalence rate." Compare *incidence*.

Private duty nursing: Services provided by a professional nurse to a patient who needs individual and continuous care beyond the level normally provided by a visiting nurse (in the home) or the nursing staff (of a hospital or skilled nursing facility).

Pulmonary surfactant: A substance present in the lungs that aids in oxygen absorption.

Quadriplegia: Paralysis of all four limbs.

Respite care: Care provided in order to give family caregivers some relief. Respite care is a broad category that can include occasional home nursing or custodial care or institutional care.

Sequelae: Aftereffects or secondary consequences.

Shift nursing: Nursing provided in the home in hourly shifts (usually 8-hour shifts), as distinguished from nursing provided in visits (usually of an hour or less). See also *private duty nursing*.

Skilled nursing care: In this technical memorandum, any care that requires highly technical nursing skills, including care provided by nonprofessionals such as parents trained in such skills.

Spina bifida: A birth defect of unknown cause that results in incomplete or improper development of the spine, usually associated with the protrusion of the spinal cord through the bony spine.

Suctioning: As it applies to children with breathing difficulties, suctioning is the removal of secretions from the airway and is particularly important when the child has a tracheostomy tube (artificial airway) that could be blocked by these secretions.

Surfactant: See *pulmonary surfactant*.

Technology-dependent children: Those children who use a medical technology (embodied in a medical device) that compensates for the loss of normal use of a vital body function, and who require substantial daily skilled nursing care to avert death or further disability.

Third-party payment: Payment by a private insurer or government program to a medical provider for care given to a patient.

Trachea: The airway extending from the back of the mouth and nose to the bronchial tubes (which lead to the lungs).

Tracheostomy: A surgical opening into the trachea. A tracheostomy tube is an artificial airway (a tube in the trachea) that opens to the outside at the tracheostomy, where it can be connected to a mechanical ventilator.

Urinary catheterization: The introduction of a tube into the urinary tract to withdraw urine.

Ventilator: A mechanical device used to assist in or control respiration by delivering an appropriate volume of gas to the airways or by promoting inspiration. In this report, it refers to both positive- and negative-pressure devices that cause or help a person to breathe.

Glossary of Acronyms

AFDC	—Aid to Families With Dependent Children
AIDS	—acquired immunodeficiency syndrome
BPD	—bronchopulmonary dysplasia
CHAMPUS	—Civilian Health and Medical Program of the Uniformed Services (Department of Defense)
CNS	—central nervous system
CSHCN	—Children with Special Health Care Needs
DOD	—US Department of Defense
EPSDT	—Early and Periodic Screening, Diagnosis and Treatment (program)
ERISA	—Employee Retirement Income Security Act
GAO	—General Accounting Office (U.S. Congress)

HCFA	—Health Care Financing Administration (DHHS)
ICD-9-CM	—International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM)
ICF	—intermediate care facility
ICU	—intensive care unit
LPN	—licensed practical nurse
LVN	—licensed vocational nurse
MCH	—Maternal and Child Health (program)
MNIL	—medically needy income level
NIH	—National Institutes of Health (PHS)
NHIS	—National Health Interview Survey
OTA	—Office of Technology Assessment (U.S. Congress)
PFTH	—Program for the Handicapped (CHAMPUS)
PHC	—Pediatric Home Care
RDS	—respiratory distress syndrome
REACH	—Rural Efforts to Assist Children at Home
RN	—registered nurse
SNF	—skilled nursing facility
SPRANS	--Special Projects of Regional and National Significance
SSI	—Supplemental Security Income (program) (SSA)

References

References

1. Ad Hoc Committee, Respiratory Care Section, American College of Chest Physicians, "Long-Term Mechanical Ventilation: Guidelines for Management in the Home and at Alternate Community Sites," *Chest* 90(1,supp.):1S-37S, July 1986.
2. Affeldt, J.E., Bower, A.G., Dail, C.W., et al., "Prognosis for Respiratory Recovery in Severe Poliomyelitis," *Arch. Phys. Med. Rehab.* 38:290-295, January-June 1957.
3. Aitken, M.J., and Aday, L.A., *Home Care for the Chronically Ill and/or Disabled Technology Assisted Child: An Evaluation Model*, unpublished, November 1985.
4. Alexander, M.A., Johnson, E.W., Petty, J., et al., "Mechanical Ventilation of Patients With Late Stage Duchenne Muscular Dystrophy: Management in the Home," *Arch. Phys. Med. Rehab.* 60:289-292, July 1979.
5. American Medical Association, Department of State Legislation, Public Affairs Group, *State Health Legislation Report*, vol. 14, No. 1 (Chicago, IL: AMA, February 1986).
6. Antoniskis, A., Anderson, B.C., Van Volkinburg, E.J., "Feasibility of Outpatient Self-Administration of Parenteral Antibiotics," *West. J. Med.* 128(3):203-206, March 1978.
7. Arnett, R.H., and Trapnell, G.R., "Private Health Insurance: New Measures of a Complex and Changing Industry," *Health Care Financing Review* 6(2):31-42, winter 1984.
8. Association of State and Territorial Health Officials Foundation, *Public Health Agencies 1983, Vol. 1: Expenditures and Sources of Funds* (Washington, DC: ASTHO, August 1985).
9. Avery, M.E., "Antepartum Glucocorticoids and Prevention of Respiratory Distress Syndrome," paper presented at the XVIII International Congress of Pediatrics, Honolulu, HI, July 7, 1986.
10. Avery, M.E., Boston Children's Hospital, Boston, MA, personal communication, July 1986.
11. Avery, M.E., Tooley, W.H., Keller, J.B., et al., "Is Chronic Lung Disease in Low Birth Weight Infants Preventable? A Survey of Eight Centers," *Pediatrics* 79(1):26-30, January 1987.
12. Bach, J., Albe, A., Pilkington, L.A., et al., "Long-Term Rehabilitation in Advanced Stage of Childhood Onset, Rapidly Progressive Muscular Dystrophy," *Arch. Phys. Med. Rehab.* 62:328-331, 1981.
13. Banaszak, E.F., Travers, H., Frazier, M., et al., "Home Ventilator Care," *Respiratory Care* 26(12): 1262-1268, December 1981.
14. Barker, E., Fairfax County School District, Fairfax, VA, personal communication, July 1986.
15. Bates, J., San Diego Children's Hospital, San Diego, CA, personal communication, July 1986.
16. Beckett, J., Child Health Specialty Clinics, Iowa City, IA, personal communication, April 1986.
17. Bennett, F.C., Robinson, N.M., and Sells, C.J., "Growth and Development of Infants Weighing Less Than 800 Grams at Birth," *Pediatrics* 71(3): 319-323, 1983.
18. Berriman, A.E., "CHAMPUS Homecare Coverage," *Homecare Rental/Sales* 6(9):74-78, September 1984.
20. Blue Cross/Blue Shield Association, *Home Health Care Survey Report* (Chicago, IL: Blue Cross/Blue Shield Association, April 1985).
21. Blue Cross/Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicago, IL: Blue Cross/Blue Shield Association, January 1986).
22. Boodman, S.G., "Born Dying: AIDS' 2nd Generation," *Washington Post*, p. A1, A8, Mar. 23, 1987.
23. Brakebill, J.I., Robb, R.A., Ivey, M.F., et al., "Pharmacy Department Costs and Patient Charges Associated With Home Parenteral Nutrition Program," *Am. J. Hosp. Pharm.* 40(2):260-263, February 1983.
24. Brooten, D., Kumar, S., Brown, L.P., et al., "A Randomized Clinical Trial of Early Hospital Discharge and Home Follow-Up of Very-Low-Birth-Weight Infants," *New Eng. J. Med.* 315(15):934-939, Oct. 9, 1986.
25. Buckwald, S., Zorn, W.A., and Egan, E.A., "Mortality and Follow-Up Data for Neonates Weighing 500 to 800 G at Birth," *Am. J. Dis. Child.* 138:779-782, 1984.
26. Burr, B.H., Guyer, B., Todres, I.D., et al., "Home Care for Children on Respirators," *N. Eng. J. Med.* 309(21):1319-1323, Nov. 24, 1983.
27. Butler, J.A., Budetti, P., McManus, M.A., et al., "Health Care Expenditures for Children With Chronic Illnesses," *Issues in the Care of Children With Chronic Illness*, N. Hobbs and J.M. Perrin (eds.) (San Francisco: Jossey-Bass, 1985).
28. Cabin, B., "Cost-Effectiveness of Pediatric Home Care," *Caring* IV(5):48-51, May 1985.
29. California Department of Health Services, Medi-

Cal Policy Division, "Reimbursement Study: Subacute Level of Skilled Nursing Facility Care," Report No. 01-86-3, August 1986.

30. California Department of Health Services, "Notice of Public Availability Pursuant to Government Code Section 11346.8 of Changes to Emergency Regulations and Supporting Documents and Information Regarding Subacute Level of Care (R-54-85)," Aug. 27, 1986.
31. Cane, R.D., and Shapiro, B.A., "Mechanical Ventilatory Support," *J.A.M.A.* 254(1):87-92, July 5, 1985.
32. Care for Life, "Life Sustaining Technologies and the Elderly: Prolonged Mechanical Ventilation, Data on Utilization and Cost," paper prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, October 1985.
33. Chollet, D.J., *Employer-Provided Health Benefits: Coverage, Provisions and Policy Issues* (Washington, DC: Employee Benefit Research Institute, 1984).
34. Cleverly, G., Human Services Department, Santa Fe, NM, personal communication, August 1986.
35. Colbert, A.P., and Schock, N.C., "Respirator Use in Progressive Neuromuscular Diseases," *Arch. Phys. Med. Rehab.* 66:760-762, November 1985.
36. Colton, M., and Gittler, J., *The Title V State Programs and the Provision of Case Management Services for Children With Special Health Care Needs* (Iowa City, IA: National Maternal and Child Health Resource Center, 1986).
37. Cooper, R., Department of Health and Social Services, Madison, WI, personal communication, February 1986.
38. Culley, T., Aetna Life and Casualty, Hartford, CT, personal communication, April 1986.
39. Curran, F.J., "Night Ventilation by Body Respirators for Patients in Chronic Respiratory Failure Due to Late Stage Duchenne Muscular Dystrophy, *Arch. Phys. Med. Rehab.* 62:270-274, 1981.
40. Curran, J.W., Morgan, W.M., Hardy, A.M., et al., "The Epidemiology of AIDS: Current Status and Future Prospects," *Science* 229:1352-1357, Sept. 27, 1985.
42. Donn, S., "Cost Effectiveness of Home Management of Bronchopulmonary Dysplasia" (letter), *Pediatrics* 70(2):330-331, August 1982.
43. Doran, T.A., Surfer, P., MacMurray, B., et al., "Results of a Double-Blind Controlled Study on the Use of Betamethasone in the Prevention of Respiratory Distress Syndrome," *Am. J. Obstet. Gyn.* 136:313-320, 1980.
44. Doyle, L.W., Kitchen, W.H., Ford, G.W., et al., "Effects of Antenatal Steroid Therapy on Mortality in Very Low Birth Weigh Infants," *J. Pediatrics* 108:287-292, 1986.
45. Driscoll, J.M, Driscoll, Y.T., Steir, M.E., et al., "Mortality and Morbidity in Infants Less Than 1,001 Grams Birth Weight," *Pediatrics* 69(1):21-26, 1982.
46. Dudrick, S.J., Winmore, D.W., Vars, H.M., et al., "Long-Term Total Parenteral Nutrition With Growth and Development and Positive Nitrogen Balance," *Surgery* 64:134-142, 1968.
47. Duggar, B., Pollatsek, J., Han, C., et al., "Financing Care of Chronically Ill and Disabled Children in Home and Other Ambulatory Care Settings," LaJolla Management Corp., Rockville, MD, April 1986.
48. Dzierba, S.H., Mirtallo, J.M., Graner, D.W., et al., "Fiscal and Clinical Evaluation of Home Parenteral Nutrition," *Am. J. Hosp. Pharm.* 41:285-291, February 1984.
49. Ellman, F.M., National Association of State Directors of Special Education, Inc., Washington DC, personal communication, January 1986.
50. Eron, L.J., "Intravenous Antibiotic Administration in Outpatient Settings," *Infectious Dis.* 14(1): 4-11, January 1984.
51. Evans, R.G., and Robinson, G.C., "An Economic Study of Cost Savings on a Care-By-Parent Ward," *Medical Care* 21(8):768-782, August 1983.
52. Farley, P.J., "Who Are the Underinsured?" *Health & Society* 63(3):476-503, 1985.
53. Farley, P., and Walden, D., "The Privately Insured Under Age 65: Cost-Sharing, Depth of Benefits and Other Aspects of their Health Insurance," presented to the American Public Health Association, 1983.
54. Feinberg, E.A., "Family Stress in Pediatric Home Care," *Caring* IV(5):38-41, May 1985.
55. Feldman, J., and Tuteur, P.G., "Mechanical Ventilation: From Hospital Intensive Care to Home," *Heart & Lung* 11(2):162-165, March/April 1982.
56. Fitzgerald, J.M., John Hancock Mutual Life Insurance Co., Boston, MA, personal communication, March 1986.
57. Foster S., and Hoskins, D., "Home Care of the Child With a Tracheostomy Tube," *Ped. Clin. No. Am.* 28(4):855-857, November 1981.
58. Fox, H.B., and Yoshpe, R., "Private Health In-

surance Coverage of Chronically Ill Children," prepared for the National Center for Networking Community-Based Services, Georgetown University Child Development Center, Washington, DC, March 1986.

59. Fox, H.B., and Yoshpe, R., "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U.S. Congress, August 1986.
60. Frame, C., "Parent of Ventilator-Dependent Child Welcomes Waiver," *AARTimes* 8(4):55, April 1984.
61. Frates, R.C., Jr., and Splaingard, M.L., "Home Care for Children on Respirators" (letter), *N. Eng. J. Med.*, 310(17):1126-1127, Apr. 26, 1984.
62. Frates, R.C., Jr., Splaingard, M.L., Smith, E.O., et al., "Outcome of Home Mechanical Ventilation in Children," *J. Pediatrics* 106(5):850-856, May 1985.
63. Gallin, R.S., and Given, C.W., "The Concept and Classification of Disability in Health Interview Surveys," *Inquiry* XIII(4):395-407, December 1976.
64. Gaumer, G.L., Birnbaum, H., Pratter, F., et al., "Impact of the New York Long-Term Home Health Care Program," *Medical Care* 24(7):641-653, July 1986.
65. Giovannoni, R., "Chronic Ventilator Care: From Hospital to Home," *Respiratory Therapy* 29(7): 29-33, July/August 1984.
66. Gitlin, J.D., Soll, R.F., Parad, R.B., et al., "A Randomized Controlled Trial of Exogenous Surfactant for the Treatment of Hyaline Membrane Disease," *Pediatric Research* 20:429A, 1986.
67. Goldberg, A.I., "Home Care for the Ventilator-Dependent Person in England and France," *Caring* IV(5):34-36, May 1985.
68. Goldberg, A.I., "The Illinois Plan," *Report of the Surgeon General's Workshop on Children With Handicaps and Their Families*, DHHS Pub. No. PHS-83-50194 (Washington, DC: U.S. Department of Health and Human Services, Public Health Service, 1983).
69. Goldberg, A.I., Faure, E.A., Vaughn, C.J., et al., "Home Care for Life-Supported Persons: An Approach to Program Development," *J. Pediatrics* 104(5):785-795, May 1984.
71. Goldberg, R.N., and Bancalari, E., "Bronchopulmonary Dysplasia: Clinical Presentation and the Role of Mechanical Ventilation," *Respiratory Care* 31(7):591-598, July 1986.
72. Gortmaker, S.L., and Sappenfield, W., "Chronic Childhood Disorders: Prevalence and Impact," *Ped. Clin. No. Am.* 31(1):3-18, February 1984.
73. Guyot, D., Albert Einstein College of Medicine, Bronx, NY, personal communication, June 1986.
74. Hack, M., and Fanaroff, A.A., "Changes in the Delivery Room Care of the Extremely Small Infant (<750 g)—Effects on Morbidity and Outcome," *N. Eng. J. Med*. 314(10):660-664, 1986.
75. Hadley, J., and Feder, J., "Hospital Caring for Children: Financial Status and Care to the Poor, 1980 and 1982," Georgetown University Center for Health Policy Studies, working paper No. 655-1, May 1985.
76. Halliday, H.L., McClure, G., Reid, M.M., et al.,"Controlled Trial of Artificial Surfactant to Prevent Respiratory Distress Syndrome," *Lancet* 1:476-478, 1984.
77. Hardy, D.R., "Adoption of Children With Special Needs: A National Perspective," *American Psychologist* 39(8):901-904, August 1984.

77a. Harris, J., "Price Rules for Hospitals," *Bell Journal of Economics* 10:224, 1979.

78. Harris, L.F., Buckle, T.F., and Coffey, F.L., "Intravenous Antibiotics at Home," *Southern Med. J.* 79(2):193-196, February 1986.
79. Harwood, I., Hernried, L., Lemen, R., et al., "Therapeutic Profiles of Cystic Fibrosis Patients Obtained From a Multi-Center Clinical Encounter," *Chest* 86(6, supp):4814, abstract, June 1986.
80. Health Insurance Association of America, *New Group Health Insurance* (Washington, DC: HIAA, 1984).
81. Heaphey, L.L., The Oley Foundation, Albany, NY, personal communication, August 1986.
82. Hedrick, S.C., and Inui, T.S., "The Effectiveness and Cost of Home Care: An Information Synthesis," *Health Services Research* 20(6, part II):851-880, February 1986.
83. Hewitt Associates, *Salaried Employee Benefits Provided by Major U.S. Employers: A Comparison Study, 1979 Through 1984* (Lincolnshire, IL: Hewitt Associates, 1985).
84. Horbar, J.D., "A Multicenter Survey of 28 Day Survival Administration in Infants 701-1500 Grams," paper presented at the Ross Laboratories Conference on Topics on Neonatality, Washington, DC, Dec. 7-9, 1986.
85. Hoskins, E.M., Elliott, E., Shennan, A.T., et al., "Outcome of Very Low-Birth Weight Infants Born at a Perinatal Center," *Am. J. Obstet. Gyn*. 145:135-140, 1983.
86. Houts, P.S., Lipton, A., Harvey, H.A., et al., "Nonmedical Costs to Patients and Their Families Associated With Outpatient Chemotherapy," *Cancer* 53(11):2388-2392, June 1, 1984.

87. Hunter, G., and Johnson, S.H., "Physical Support Systems for the Homebound Oncology Patient," as cited in Joint Commission on Accreditation of Hospitals, "Guidelines for Evaluating Home Infusion Therapy Services," prepared for Blue Cross and Blue Shield Association, Chicago, IL, 1986.
88. Intergovernmental Health Policy Project, "State Regulation of Subacute Care: A 50-State Survey," *Focus On . . .*, No. 12, October 1986.
89. Jobe, A., "Surfactant Treatment for Respiratory Distress Syndrome," *Respiratory Care* 31(6): 467-479, June 1986.
90. Jordan, M., "Foster Parent Scarcity Causing Crisis in Care," *Washington Post*, p. F1, F8, July 20, 1986.
91. Kacmarek, R.M., comments following Kacmarek, R.M., and Thompson, J.E., "Respiratory Care of the Ventilator-Assisted Infant in the Home," *Respiratory Care* 31(7):613, July 1986.
92. Kahn, L., "Ventilator-Dependent Children Heading Home," *Hospitals* 58(5):54-55, Mar. 1, 1984.
93. Kaufman, J., Coordinating Center for Home and Community Care, Inc., Millersville, MD, personal communication, May 1986.
94. Keister, H., Department of Public Welfare, Harrisburg, PA, personal communication, August 1986.
95. Kelly, D.A., Armitstead, J.A., and Walker-Smith, J.A., "Home Parenteral Nutrition for Children" (letter), *Lancet* 2(8509):746, Sept. 27, 1986.
96. Kind, A.C., Williams, D.N., Persons, G., et al., "Intravenous Antibiotic Therapy at Home," *Arch. Int. Med.* 139:413-415, April 1979.
97. Kirkhart, K., Children's Hospital, New Orleans, LA, personal communications, February 1986 and December 1986.
98. Kisker, C.T., *The Needs of Children With Cancer: A Comprehensive View* (Iowa City, IA: The University of Iowa, 1983).
99. Klaus, M.H., and Fanaroff, A.A., *Care of the High-Risk Neonate*, 2d ed. (Philadelphia, PA: W.B. Saunders, 1979).
100. Konishi, M., Fujiwara, T., Naito, T., et al., "Surfactant Replacement Therapy in Neonatal Respiratory Distress Syndrome (RDS)—A Prospective Collaborative Study," paper presented at the XVIII International Congress of Pediatrics, Honolulu, HI, July 7, 1986.
101. Laudicina, S.S., *A Comparative Survey of Medicaid Hospital Reimbursement Systems for Inpatient Services, State by State, 1980-1985* (Washington, DC: The Urban Institute, 1986).
102. Lauri, B., "Polio Survivors Prove the Value of Home Care Services," *AARTimes* 8(4):47-50, April 1984.
103. Lee, G.B., "Development of a Home Health Case Management Program in Los Angeles County," California Children Services, Department of Health Services, County of Los Angeles, Oct. 31, 1983.
104. Lis, E., Crippled Children's Services, Chicago, IL, personal communication, April 1986.
105. Lyons, J.M., Falkenbach, K., and Cerra, F.B., "Home Parenteral Nutrition With Full-Time Home Care Nurses," *J.P.E.N.* 5(6):528-530, November/December 1981.
106. MacQueen, J.C., "Implications for Care: The Title V Perspective," *Report of the Surgeon General's Workshop on Children With Handicaps and Their Families*, U.S. Department of Health and Human Services, Public Health Service, DHHS Pub. No. (PHS) 83-50194 (Washington, DC: U.S. Government Printing Office, 1983).
107. MacQueen, J.C., "Future Directions of Services for Children With Special Health Care Needs," paper presented at the Annual Meeting of the Association for MCH/CC Programs, Washington, DC, Mar. 19, 1984.
108. MacQueen, J.C., "Alternatives to Hospital Care," unpublished, Aug. 5, 1986.
109. Matthews, L.W., and Drotar, D., "Cystic Fibrosis —A Challenging Long-Term Disease," *Ped. Clin. No. Am.* 31(1):133-152, February 1984.
110. Mayhue, H., Bureau of Data Management and Strategy, Health Care Financing Administration, U.S. Department of Health and Human Services, Baltimore, MD, personal communication, Feb. 11, 1987.
111. McDonnell, P., Division of National Cost Estimates, Health Care Financing Administration, U.S. Department of Health and Human Services, Baltimore, MD, personal communication, Mar. 5, 1987.
112. McInerny, T., "The Role of the General Pediatrician in Coordinating the Care of Children With Chronic Illness," *Ped. Clin. No. Am.* 31(1):199-209, February 1984.
113. McManus, M.A., Melus, S.E., Norton, C.H., et al., *Guide to National Data on Maternal and Child Health* (Washington, DC: McManus Health Policy, Inc., 1986).
114. Michigan Department of Public Health, Division of Services to Crippled Children, *Guidelines for Home Care of Responauts, Task Force Report* Aug. 14, 1984.
115. Middlemiss, R., Casa Colina Skilled Rehabili-

tation Center, Los Angeles, CA, personal communication, August 1986.

116. Mikol, M., SKIP (Sick Kids [need] Involved People) of New York, Inc., New York, NY, personal communication, April 1986.

117. Milofsky, C., and Elworth, J.T., "Charitable Associations," *Issues in the Care of Children With Chronic Illness*, N. Hobbs and J.M. Perrin (eds.) (San Francisco, CA: Jossey-Bass, 1985).

118. Monahan, C.A., "Safety and Monitoring of Home Ventilators," paper presented to the Interagency Technical Committee Working Group on Lung Diseases, Bethesda, MD, Feb. 17, 1987.

119. Monahan, G.H., and Schkade, J.K., "Comparing Care by Parent and Traditional Nursing Units," *Pediatric Nursing* 11(6):463-468, November-December 1985.

120. Murray, N., Omaha, NE, personal communication, July 1986.

121. National Association of Employers on Health Care Alternatives, Survey of National Corporations on Health Care Cost Containment, D.J. Chollet, *Employer-Provided Health Benefits: Coverage, Provisions and Policy Issues* (Washington, DC: Employee Benefit Research Institute, 1984).

122. New York Academy of Medicine, "Registry of Patients on Home Total Parenteral Nutrition (TPN)," unpublished data, 1982.

123. Newacheck, P.W., Budetti, P.P., and Halfon, N., "Trends in Activity-Limiting Chronic Conditions Among Children," *Am. J. Public Health* 76(2):178-184, February 1986.

124. Newacheck, P.W., Budetti, P.P., and McManus, P., "Trends in Childhood Disability," *Am. J. Public Health* 74(3):232-236, March 1984.

126. Oley Foundation, Inc., "Nutritional Support and Hydration for Critically and Terminally Ill Elderly: Utilization in the Home," contract paper prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, September 1985.

127. Olson, H.H., "Home Care of the Ventilator-Dependent Child," *Caring* V:48-54, December 1984.

128. Perry, B., and Lierman, C.,"Hospital Based Pediatric Home Care: Review of the Issue and a Case Example," report submitted to the Robert Wood Johnson Foundation, June 28, 1985.

129. Pierce, P.M., and Freedman, S.A., "The REACH Project: An Innovative Health Delivery Model for Medically Dependent Children," *Children's Health Care* 12(2):86-89, Fall 1983.

130. Poretz, D.M., Eron, L.J., Goldenberg, R.I., et al., "Intravenous Antibiotic Therapy in an Outpatient Setting," *J.A.M.A.* 248(3):336-339, July 16, 1982.

131. Rehabilitation Institute of Chicago, National Foundation—March of Dimes, Care for Life, and Rehabilitation Gazette, "What Ever Happened to the Polio Patient?" Proceedings of an international symposium, Chicago, IL, Oct. 14-16, 1981.

132. Rehm, S.J., and Weinstein, A.J., "Home Intravenous Antibiotic Therapy: A Team Approach," *Ann. Int. Med.* 99(3):388-392, September 1983.

133. Rohrer, J.E., Smith, D.W. and Hogan, A.J., "Long-Term Care Patient Assessment: Evaluation of a Methods Effect," *Medical Care* 24(8): 687-693, August 1986.

134. Rosenbaum, S., "Children and Private Health Insurance," *Recent Developments in the Financing and Organization of Health Care: Implications for Children* (in press).

135. Rosenbaum, S., "The Prevention of Infant Mortality: The Unfulfilled Promise of Federal Health Programs for the Poor," *Clearinghouse Review* pp. 726-729, November 1983.

136. Roughan, J., The Equitable Life Assurance Co., La Brea, CA, personal communication, June 1986.

137. Rucker, B.B., and Holmstedt, K.A., *Home Infusion Therapy Industry* (San Francisco, CA: Hambrecht & Quist, April 1984).

138. Saigal, S., Rosenbaum, P., Stoskopf, B., et al., "Outcome in Infants 501 to 1000 Gm Birth Weight Delivered to Residents of the McMaster Health Region," *J. Pediatrics* 105:969-976, 1984.

139. Scalese, J.P., Voorhees Pediatric Facility, Gibbsboro, NJ, personal communication, December 1986.

140. Schneider, D.P., Fries, B.E., Foley, W.J., et al., "Development of RUG II Case Mix Measurement System for Long Term Care," *Proceedings of the Annual Conference of the Health Service Division, IIE* (Chicago, IL: American Hospital Association, February 1986).

141. Schraeder, B.D., "A Creative Approach to Caring for the Ventilator-Dependent Child," *M.C.N.* 4:165-170, May/June 1979.

142. Shannon, K., SKIP (Sick Kids [need] Involved People), Inc., Severna Park, MD, personal communication, December 1986.

143. Shapiro, D., Rochester, NY, personal communication, 1986.

144. Shapiro, S., McCormick, M.C., Starfield, B.H., et al., "Changes in Infant Morbidity Associated With Decreases in Neonatal Mortality," *Pediatrics* 72(3):408-415, 1983.

145. Shapiro, D.L., Rosenberg, P., "The Effect of

Federal Regulations Regarding Handicapped Newborns: A Case Report," *J.A.M.A.* 252:2031-2033, 1984.

146. Sherman, M., McLean, D., Zorn, E., et al., "Home Care for Ventilator-Dependent Patients: A Rational Option" (abstract), *Respiratory Care* 27(10):1252, October 1982.
147. Sivak, E.D., Cordasco, E.M., and Gipson, W.T., et al., "Pulmonary Mechanical Ventilation at Home: A Reasonable and Less Expensive Alternative," *Respiratory Care* 28(1):42-49, January 1983.
148. Splaingard, M.L., Frates, R.C., Harrison, G.M., et al., "Home Positive-Pressure Ventilation," *Chest* 84(4):376-382, October 1983.
149. Splaingard, M.L., and Splaingard, D., "Home Care of the Ventilator-Dependent Child: Realities and Limitations," *Pride Institute Journal of Long Term Home Health Care* 5(2):15-20, spring 1986.
150. Stein, R.E., and Jessop, D.J., "Does Pediatric Home Care Make a Difference for Children With Chronic Illness? Findings From the Pediatric Ambulatory Care Treatment Study," *Pediatrics* 73(6):845-853, June 1984.
151. Stiver, H.G., Telford, G.O., Mossey, J.M., et al., "Intravenous Antibiotic Therapy at Home," *Ann. Int. Med.* 89(5, part 1):690-693, November 1978.
152. Sulvetta, M.B., and Swartz, K., *The Uninsured and Uncompensated Care* (Washington, DC: National Health Policy Forum, George Washington University, June 1986).
153. Tarnow-Mordi, W., and Wilkinson, A., "Mechanical Ventilation of the Newborn," *Br. Med. J.* 292:575-576, 1986.
154. Taussig, L.M., "Bronchopulmonary Dysplasia," *Follow-Up of the High Risk Newborn—A Practical Approach*, E.J. Sell (ed.) (Springfield, IL: Charles C. Thomas, 1980).
155. Thomas, E., Blue Cross/Blue Shield Federal Employees Benefit Program, Washington, DC, personal communication, 1986.
156. Thomas, R.B., "Ventilator Dependency Consequences for Child and Family," unpublished Ph.D. dissertation, University of Washington, 1986.
157. Tschumper, P., Department of Health and Social Services, Madison, WI, personal communication, April 1986.
158. U.S. Congress, General Accounting Office, *Maternal and Child Health Block Grant: Program Changes Emerging Under State Administration*, GAO/HRD-84-35 (Washington, DC: U.S. General Accounting Office, May 7, 1984).
159. U.S. Congress, House of Representatives, Committee on Ways and Means, *Background Material and Data on Programs Within the Jurisdiction of the Committee on Ways and Means, 1986* WMCP 99-14, Mar. 3, 1986.
160. U.S. Congress, House of Representatives, Select Committee on Aging, *The "Black Box" of Home Care Quality*, August 1986.
161. U.S. Congress, Office of Technology Assessment, *Federal Policies and the Medical Devices Industry*, OTA-H-230 (Washington, DC: U.S. Government Printing Office, October 1984).
162. U.S. Congress, Office of Technology Assessment, *Technology and Child Health*, draft, Washington DC, 1987.
163. U.S. Department of Commerce, Bureau of the Census, *1976 Survey of Institutionalized Persons: A Study of Persons Receiving Long-Term Care*, Current Population Reports Special Studies, series P-23, No. 69, June 1978.

163a. U.S. Department of Commerce, Bureau of the Census, Current Population Survey, unpublished data, March 1986.

164. U.S. Department of Defense, Office of the Assistant Secretary of Defense, *Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)*, DOD 6010.8-R, March 1986.
165. U.S. Department of Education, Office of Special Education, *9th Annual Report to Congress on the Implementation of the Education of the Handicapped Act*, 1987.
166. U.S. Department of Health and Human Services, Health Care Financing Administration, Bureau of Data Management and Strategy, "End Stage Renal Disease Patient Profile Tables," 1985.
167. U.S. Department of Health and Human Services, Health Care Financing Administration, *Health Care Financing Program Statistics: Analysis of State Medicaid Program Characteristics, 1984* (Baltimore, MD: DHHS, August 1985).
168. U.S. Department of Health and Human Services, Health Care Financing Administration, *Medicaid Data Book 1983* (Washington DC: DHHS, 1985).
169. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, personal communication, 1986.
170. U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, *A Study of Infant Mortality From Linked Records By Birth Weight, Period of Gestation, and Other Variables, United States, 1960 Live-Birth Cohort*, DHEW Pub. No. (PHS) 79-1055, (Hyattsville, MD: NCHS, May 1972).

171. U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, "Advance Report of Final Natality Statistics, 1984, Table 24," *Monthly Vital Statistics Report*, 35 (4, suppl.):37, July 18, 1986.
172. U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, "Detailed Diagnoses and Procedures for Patients Discharged from Short-Stay Hospitals, United States, 1984," *Vital and Health Statistics* Series 13, No. 86, DHHS Pub. No. 86-1747, (Washington, DC: U.S. Government Printing Office, April 1986).
173. U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, *Infantile Apnea and Home Monitoring* (draft), Bethesda, MD, 1986.
174. U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, *Prevention of Respiratory Distress Syndrome, Effect of Antenatal Dexamethasone Administration*, NIH Pub. No. 85-2695 (Washington, DC: NIH, August 1985).
175. U.S. Department of Labor, Bureau of Labor Statistics, *Employee Benefits in Medium and Large Firms, 1984,* Bulletin 2237, (Washington, DC: U.S. Government Printing Office, June 1985).
176. Valdez, K., Human Services Department, Santa Fe, NM, personal communication, July 1986.
177. Van Dyck, P.C., "The Crippled Children Services Program," *Workshop on Financing Health Care for Handicapped Children* (Rockville, MD: U.S. Department of Health and Human Services, January 1984).
178. Ventilator Assisted Care Program, Children's Hospital, New Orleans, LA, "The Ventilator Assisted Population in Louisiana," unpublished, Sept. 21, 1985.
179. Walker, D.K., "Care of Chronically Ill Children in Schools," *Ped. Clin. No. Am.* 31(1):221-233, February 1984.
180. Walker, L.S., Ford, M.B., and Donald, W.D., "Cystic Fibrosis and Family Stress: Effects of Age and Severity of Illness," *Pediatrics* 79(2): 239-246, February 1987.
181. Wateska, L.P., Sattler, L.L., and Steiger, E., "Cost of a Home Parenteral Nutrition Program," *J.A.M.A.* 244(20):2303-2304, Nov. 21, 1980.
182. Weissert, W.G., Scanlon, W.J., Wan, T.T.H., et al., "Care for the Chronically Ill: Nursing Home Incentive Payment Experiment," *Health Care Financing Review* 5(2):41-49, Winter 1983.
183. Wilkinson, A., Jenkins, P.A., and Jeffrey, J.A., "Two Controlled Trials of Dry Artificial Surfactant: Early Effects and Later Outcome in Babies with Surfactant Deficiency," *Lancet* 2:287-291, 1985.
184. Wood, S.P., Walker, D.K., and Gardner, J., "School Health Practices for Children With Complex Medical Needs," *J. School Health* 56(6):215-217, August 1986.
185. Worley, G., Duke University Medical Center, Durham, NC, personal communication, July 1986.
186. Wyatt Co., *1984 Group Benefits Survey* (Washington, DC: The Wyatt Co., 1984).
187. Zill, N., *The School-Aged Handicapped,* prepared for the National Center for Education Statistics, U.S Department of Education, NCES-85-400 (Washington, DC: U.S. Government Printing Office, January 1985).

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The Technology Assessment Board is composed of six members of the House, six members of the Senate, and the OTA Director, who is a nonvoting member.

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